NDIS Review

Working together to deliver the NDIS

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Independent Review into the National Disability Insurance Scheme

Final Report

Supporting Analysis

Copyright and ISBN

Introduction

1.   Acknowledgement of Country

We acknowledge the Traditional Owners and Custodians of Country across this nation on whose lands we all work, play and live. We acknowledge their ongoing connection to land, waters and community. We pay our respect to Elders past, present and emerging. We extend that respect to all First Nations people. They continue to undertake disproportionate care to sustain this land, their families and communities while facing the ongoing effects of colonisation.

2.   A word on language and disability

In this report, we use the term 'disability' in the context of the internationally recognised social model of disability. This is a commitment by all Australian governments and describes disability as a social construct. Under this model, intersecting societal barriers are the obstacles to equal participation, not people's impairment.

We use person-first language in this report - person with disability. We acknowledge, however, that preferences vary between different disability communities. Where possible, we have tried to use language commonly used or preferred by a community. We have also reflected the language used in submissions received by the Review. This means sometimes our language is not consistent.

We also at times refer to the very important role of 'family and carers' in the lives of people with disability. In using this term, we wish to make clear that it is meant to be all-embracing. It includes parents, siblings, allies and supporters who play very important roles in the lives of people with disability, both individually and collectively.

3.   Definitions and glossary

In this report we use a range of specialist, technical words and expressions. Some of these words are well known within the disability community. At other times, technical terms can have a different meaning when applied to the working of the scheme. A glossary with key words and their definitions and a list of acronyms is in Appendix A.

4.   Content warning

This report contains material that may be triggering or upsetting for some readers. If you need support at any time, you can contact the following confidential services which are available 24 hours a day, 7 days a week:

- Beyond Blue Support Service - 1300 224 636 or www.beyondblue.org.au
- Lifeline Crisis Support - 13 11 14 or www.lifeline.org.au
- 1800Respect - 1800 737 732 www.1800respect.org.au
- 13YARN - 13 92 76 www.13yarn.org.au

If you would like to report a specific incident involving an NDIS provider or worker, contact the NDIS Quality and Safeguards Commission: 1800 035 544 www.ndiscommission.gov.au/complaints

5. Introduction

Our final report of the National Disability Insurance Scheme Review – *Working together to deliver the NDIS* – outlines 26 recommendations and 139 actions to deliver on the three overarching objectives of the terms of reference:

- putting people with disability back at the centre of the NDIS
- restoring trust, confidence and pride in the NDIS
- ensuring the sustainability of the NDIS for future generations.

This document provides supporting analysis on the recommendations in the final report. It is designed for those with a deep interest in the NDIS. It provides more detail on the findings, considerations and analysis that contributed to development of our recommendations. It also provides detailed implementation guidance to assist policy makers and regulators.

We recognise people are unlikely to read this supporting analysis cover to cover, but rather refer to the detail for their area of interest. This has shaped how we have drafted and compiled the analysis.

Chapters are structured thematically and broadly follow the order of the recommendations as they appear in the final report:

- Chapter 1: Foundational supports and mainstream services (Recommendations 1-2)
- Chapter 2: Participant pathway, including children with disability and developmental concerns and people with psychosocial disability (Recommendations 3-7)
- Chapter 3: Housing and living supports (Recommendations 8-9)
- Chapter 4: Markets and workforce (Recommendations 10-11, 13-15)
- Chapter 5: Quality and safeguards (Recommendations 12, 16-19)
- Chapter 6: Governance and outcomes (Recommendations 20-23)
- Chapter 7: Sustainability

Each chapter is organised around the recommendations from the final report. The chapter provides further analysis and evidence relating to each action in a recommendation. We have also included further information on implementation detail as a guide for governments.

The final report also contains a section on 'A five year transition' (Recommendations 24-26). This provides guidance for governments implementing our proposed reforms. These recommendations are covered at the end of this introduction and are reflected in the implementation detail throughout all chapters.

Many elements of our recommendations intersect, reflecting the unified nature of the ecosystem of disability support we recommend creating. This means some issues or the effects on some people with disability are spread across a number of recommendations. This is particularly true of recommendations relating to children with disability or developmental concerns and people with psychosocial disability. We have drawn out these interdependencies with cross-referencing. In some cases, information is repeated in relevant sections to guide the reader.

5.1. Context – What is the NDIS?

5.1.1. The NDIS provides support to people with disability, their families and carers

The NDIS funds reasonable and necessary supports for eligible Australians who are born with or acquire a permanent and significant disability. It is jointly governed and funded by the Australian, state and territory governments.

The NDIS takes a lifetime approach, investing early in people with disability and children with disability or developmental concerns to improve their outcomes later in life. It also provides a comprehensive insurance for all Australians in case they are born with or acquire a disability before the age of 65.

The NDIS is essential to Australia meeting its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This aims to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by people with disability.

As a social insurance scheme, the NDIS creates benefits for people without disability and is an important part of Australia's safety net. No one knows when they might acquire a disability or have a child or grandchild who is born with a disability and may need the NDIS. While most people may not require the NDIS, the scheme is there to provide reasonable and necessary support for every Australian if they need it. It is an investment designed to deliver social and economic benefits over the lifetime of each participant.

5.1.2. The NDIS is one of the most important global social policy innovations

It is easy to forget how bold a step the NDIS was - and is. No other nation has anything like it. Today it is one of the pillars on which the decency and fairness of Australia society stands.

The NDIS is world leading in its development and design and is based on the premise that greater investment and support through a social insurance approach can deliver both economic and social benefits. Its progress is being watched carefully around the world.

5.1.3. Evolution and growth of the NDIS over the past decade

Before the NDIS, people with disability had to combine self-funded support with the state, territory or community services they could find, or simply go without. Government funding would go to organisations to provide these supports, which meant people with disability had little choice over what supports they received and who provided them.

The NDIS resulted from decades of policy thinking and community campaigning. The idea of it gained momentum in Australia at a national level in 2008, when the idea was adopted following the 2020 Summit.[1]

Over the next three years, a series of events created the case for change that saw the NDIS become the greatest and long-standing reform outcome of the 2020 Summit.

In 2009, the Productivity Commission was tasked to examine the viability of a disability insurance scheme as part of its Inquiry into Disability Care and Support. Concurrently, in 2010 people with disability, their families and carers and service providers joined forces to create Every Australian Counts - a grassroots campaign that drew on support from more than 200,000 ordinary Australians. Every Australian Counts galvanised public and political support for the NDIS.

The Productivity Commission released the results of its landmark Inquiry in 2011, finding the existing disability services system was "underfunded, unfair, fragmented, and inefficient". It argued a new disability system was needed to provide more equitable and efficient disability support across the country.

> *"There should be a new national scheme — the National Disability Insurance Scheme — that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare)." - Productivity Commission* [2]

All governments in Australia adopted the Productivity Commission recommendations, with the Australian Government passing legislation to establish the scheme and the NDIS in March 2013.[3] On 1 July 2013, The *National Disability Insurance Scheme Act 2013* came into effect and the National Disability Insurance Agency (NDIA) was established to administer the scheme.

The NDIS was launched in four trial sites across the country that covered a combination of area-based and population group trials: the Hunter area in New South Wales, the Barwon area in Victoria, 0-14 year olds across South Australia and 15-24 year olds across Tasmania.[4]

Its introduction was a public policy miracle based on a collective desire to change Australia for the better which was enacted by all governments acting in unison. It was a practical demonstration of the nation's desire to realise its commitment to the UNCRPD.

After three years of trials, the NDIS began rolling out nationally. This roll out finished in July 2020. The NDIS now supports more than 610,000 people in 2023, including almost half who did not receive support before the scheme existed.[5]

5.1.4.   Numerous reviews have considered the NDIS and the disability support system

Since its launch, the NDIS has been the subject of many inquiries and reviews that have made a range of recommendations for change. These include:

- Productivity Commission Review of NDIS Costs (2017)
- Tune Review of the National Disability Insurance Scheme Act (2019)
- 16 reports from the Joint Standing Committee on the NDIS.

Our work builds on the issues identified by people with disability and organisations with a stake in the NDIS as part of these reviews. We have sought to identify practical ways these challenges can be addressed.

5.1.5. The NDIS Review continues this journey

On 18 October 2022, the Commonwealth Minister for the NDIS, the Hon Bill Shorten MP, established the Independent Review of the NDIS to examine the design, operations and sustainability of the scheme, including markets and workforce.[6]

With the support of ministers with responsibility for disability across the country, we undertook to do this Review differently to other government reviews by amplifying the voices of people with disability and their families, carers, representative organisations, providers and workers and their representatives. Over 10 months we heard from about 8,000 people.

5.2. The approach to our work and engagement was comprehensive

The voices of people with disability have been at the centre of our thinking. Their voices, their feedback and their ideas have resulted in a set of recommendations based on their lived experiences and expertise.

We took a three-stage approach to engagement that involved: listening to people with disability their families and organisations that supported them; seeking solutions and ideas from people on how to fix the challenges facing the scheme; and testing and seeking feedback on our ideas for change.

5.2.1. We provided a variety of ways for people to engage

We wanted to hear from as many people as possible. We provided many ways for people to be involved. We particularly wanted to create opportunities for people who don't usually participant in government reviews to have their say. This is further detailed in Appendix C to the final report, and included the following activities.

Communication platforms and submission process

We communicated on a regular basis with our community through media, social media and our website. With over 5,000 subscribers, we committed to keep people informed and to do so in accessible and easily understood ways. This included our 'Review round-up' online newsletter, news items and videos.

We also released six issues papers which provided further detail on our thinking, analysis and sought feedback and views from stakeholders. These included:

- Our Approach: Independent Review of the National Disability Insurance Scheme – 22 November 2022
- NDIS Quality and Safeguarding Framework issues paper – 17 April 2023
- NDIS Participant Safeguarding Proposals Paper – 8 May 2023
- Building a more responsive and supportive workforce – 15 May 2023
- Improving access to supports in remote and First Nations communities – 1 June 2023
- The role of pricing and payment approaches in improving participant outcomes and scheme sustainability – 1 June 2023

We welcomed submissions in different formats, including written, verbal by phone, video, Auslan, artwork and poetry. The level of engagement throughout this process was enormous.

We received 3,976 submissions from individuals and organisations. Submissions were published on our website where consent was provided.

Hosting a variety of meetings, including webinars, town hall style, large roundtables, workshops and small meetings in person, over the phone and online

We visited every state and territory, including a week-long visit to the Northern Territory which took members of the Panel and Secretariat from Darwin to Alice Springs via Maningrida, Groote Eylandt, Tennant Creek and Ali Curung. From November 2022 to September 2023 we held over 280 of our own events, meetings, roundtables and webinars. That's about 28 events every month. This included hosting two live-streamed major public events in August and September 2023, in Newcastle and Geelong, with speeches providing early insights to our reform directions.

Partnering with organisations to hold workshops, meetings and focus groups

We partnered with community organisations who organised events and activities for their communities. We hoped people would feel comfortable and safe to share their experiences if sessions were run by organisations that people trusted. We partnered with Every Australian Counts to hold virtual workshops on issues that mattered most to people, with some sessions focused on the experiences of people living in regional, rural and remote communities. We engaged Autism Queensland, as part of the national Autism Alliance, who facilitated engagement with autistic people, their families and communities through surveys, individual and group engagements, and creative submissions.

We know that Disability Representative Organisations (DROs) who represent millions of Australians with disability are trusted by their communities. Partnering with DROs, including the First Peoples Disability Network, enabled us to reach many more people, who generously shared their lived experience, insights and ideas for improvement in safe, trusted spaces. Partnering in this way also gave us the opportunity to hear the experiences of people with disability who are not often heard.

Interviews and focus group sessions with sector and technical experts

We conducted interviews and small focus group sessions with sector experts and NDIS frontline staff who work with participants and their families. We wanted to better understand, from people with lived experience and direct sector expertise, what is driving the current participant experience and what could be improved. We heard the personal stories of 1000 people with disability.

Participatory engagement with people with lived experience

For most of this year we have worked in close collaboration with a small group of people with lived experience of disability to test and improve some of our ideas. We called this stream of our work "participatory engagement". This process included sessions with people with lived experience, service providers, NDIA staff and intermediaries.

As part of this we brought together people with disability, people with operational and service delivery expertise and sector representatives in a Co-Group to help test ideas for reforming how participants interact with the NDIS. We tested views on the desirability, fairness, feasibility and sustainability of the ideas, and gathered extensive feedback on important principles and considerations for their implementation. The Co-Group played an important role in allowing us to go deeper and tackle difficult questions on how to balance competing interests and trade-offs and helped to inform the evolution of our ideas. The Co-Group's *Feedback to the NDIS Review Panel* is provided at Appendix B.

Engagement with state and territory governments

State and Territory Disability Reform Ministers were kept informed of the Review's progress through regular updates to the Disability Reform Ministerial Council. This included reporting back what we had heard and what we thought it meant for the NDIS and broader system.

The Review Secretariat also set up an NDIS Review Senior Advisory Group made up of senior disability officials from each state and territory and the Australian Government. This group was engaged regularly throughout the Review on key ideas and impacts on state and territories, through a combination of meetings and full-day workshops.

5.3. The extent of our engagement positions governments well to implement our recommendations

The reforms proposed are based on feedback from people with disability, their families, representative organisations, providers and workers, from our extensive engagement and research. As our recommendations are strongly based on feedback and input from across the disability community, we believe they should be considered as the blueprint for reform, representing the first stage of design with, and accountability to, people with disability and the sector more broadly.

For the next stage, detail should be developed and implemented in a way that is inclusive, participatory, and continues the strong engagement from the Review.

We also recognise that people with disability, their families, carers, representative organisations, workers and disability service providers are exhausted by never-ending change. There is significant reform fatigue, and everyone craves consensus and certainty around the transition to a better future for the NDIS.

Our recommended approach for transition takes these lessons into account. This includes a five-year transition period, robust design and testing of specific components with people with disability, and a focus on retaining the features of the NDIS that work well and improving or replacing those that are not.

Implementation should ensure all groups with a stake in the NDIS have a genuine voice in the process. This should be reflected in design with involvement of the disability community. It also extends to the make-up of implementation bodies and governance structures, which should prioritise inclusion of people with disability.

Implementation should carefully balance the need for deep engagement and the time this requires with ensuring that the whole of the disability support ecosystem, including the NDIS, is both equitable and sustainable, as soon as practicable.

We make three recommendations to lay the foundations for successful implementation over a five-year transition period.

Recommendation 24: Establish appropriate architecture to implement reforms

- Action 24.1: The Disability Reform Ministerial Council should agree architecture to support implementation and delivery of the NDIS reform agenda.
- Action 24.2: The new NDIS Review Implementation Advisory Committee should report to the Disability Reform Ministerial Council every six months or as needed.
- Action 24.3: The new NDIS Experience Design Office should commission agile projects to design and test reforms to the participant pathway.

Recommendation 25: Coordinate and consult on amendments to relevant legislation to enact proposed reforms

- Action 25.1: The Department of Social Services, with input from the National Disability Insurance Agency and NDIS Quality and Safeguards Commission, should review the recommendations from this Review and develop a proposed package of legislative reforms.

Recommendation 26: Develop an implementation roadmap that factors in critical dependencies and risks and ensures a smooth transition for existing participants

- Action 26.1: National Cabinet should agree and publish an implementation roadmap.
- Action 26.2: The National Disability Insurance Agency should ensure existing participants experience a smooth and fair transition to the new participant pathway.
- Action 26.3: The new NDIS Review Implementation Working Group should coordinate communications across relevant agencies to regularly update and inform stakeholders on implementation progress.

Further implementation detail is included across recommendations in this Supporting Analysis.

Chapter 1: Foundational supports and mainstream services

1.   Key messages

- The NDIS was designed to be one part of an ecosystem of supports that Australians with disability, their families and carers could rely on. The ecosystem was supposed to include mainstream services, community supports, informal supports, Tier 2 supports and NDIS individualised budgets.
- In prioritising the implementation of the NDIS, all governments have failed to adequately plan and invest in supports outside the NDIS – including mainstream services and broader community supports. This has led to insufficient support for people with disability outside the NDIS with the NDIS becoming 'an oasis in the desert'.
- This picture must change. There should be greater availability of support in "Tier 2". We have renamed Tier 2 "foundational supports". That is because these supports are the foundations of a good life for people with disability. They are also the foundations of a sustainable NDIS. Foundational supports are disability-specific supports, such as information and advice and peer support that should be available for and benefit all people with disability, families and carers outside of NDIS individualised budgets. It also includes specific supports that are targeted at meeting the needs of people not eligible for the NDIS.
- Foundational supports on their own are not enough to bridge the gap between the supports inside and outside the NDIS. We must also make sure mainstream services and communities are more culturally responsive, accessible and inclusive. We also need to improve the connection between the NDIS and other service systems.

Foundational disability supports for every Australian with disability

- Most people with disability are not in the NDIS – and never will be – because they do not require an individualised budget to have their needs met. The Productivity Commission imagined a system where all people with disability would get the support they needed to be included in their community and thrive. But this has not been the experience of many Australians with disability.
- Foundational supports are essential to a joined-up ecosystem that reduces the cliff between the support available inside and outside the NDIS. Three major reforms are required:
  - ensuring funding for foundational supports is fair and equitable and reduces the gap between what is available inside outside the scheme
  - increasing the type and level of foundational supports available for people with disability
  - improving the design and delivery and striking the right balance between innovation and short-term priorities

Inclusive mainstream services coordinated with the NDIS

- All Australians benefit from more inclusive and accessible mainstream services and communities. Despite good intentions and commitments under Australia's Disability Strategy, people with disability continue to face discrimination and barriers accessing mainstream

services and participating in their communities – leading to poorer social and economic outcomes.

- Multiple actions are required to achieve this. Our laws must take a proactive and contemporary approach to inclusion. We must strengthen accountability and transparency by measuring progress and outcomes. We need leaders and advocates to help transform communities so they are accessible and inclusive for everyone. Mainstream services and community supports must also be better connected with the NDIS and easier to navigate.

2.   Foundational Supports

- The current ecosystem of supports for people with disability is disconnected, unfair and undermines the sustainability of the NDIS. Foundational supports are essential to a joined-up ecosystem that reduces the cliff between the supports available inside and outside the NDIS. Foundational supports are a shared responsibility across Australian, state and territory governments.

- Foundational supports are disability-specific supports that are available for and benefit people with disability, families and carers outside of NDIS individualised budgets. Foundational supports are about making sure all people with disability can access the right supports, at the right time and place, to achieve their potential. Like preventative healthcare, foundational supports are amongst the most strategic investments governments can make.

- Currently there is significant lack of available and appropriate foundational supports. This results in poor social and economic outcomes for people with disability. In prioritising the implementation of the NDIS, all governments have failed to adequately plan and invest in foundational supports and address the needs of people with disability outside the NDIS. There is also no clear strategy nor accountability for the investment in or outcomes delivered by foundational supports.

- To date most of what could be considered "general foundational supports" have been delivered as part of the Information, Linkages and Capacity Building (ILC) or Partners in the Community programs. This has included activities such as information and advice and peer support. These general supports have not been funded, prioritised or delivered effectively.

- There have also been limited "targeted foundational supports" that are focused on early intervention, prevention or low intensity support needs for groups of people with disability outside the NDIS. This includes children with emerging development concerns and disability, adults with psychosocial disability and chronic health conditions.

- The result is that many people with disability apply for and stay in the NDIS for fear of lack of support outside of it, even when supports outside the NDIS may be more appropriate. People who cannot access the scheme are missing out on vital supports and services, increasing future needs. Both result in poor outcomes for people with disability. They also put financial stress on the NDIS and threaten its sustainability.

- We are recommending a new Foundational Support Strategy to ensure good planning, coordination, and accountability, with suitable governance to track and measure outcomes. The Strategy should be jointly designed, funded, and commissioned by the Australian and state and territory governments.

- Two kinds of foundational supports should be available. General foundational supports include activities such as information and advice and peer support and should be available to all people with disability (and where appropriate their families). Targeted foundational supports are focused on population groups such as children or people with a psychosocial disability. These are specific supports for those not eligible for the NDIS and whose needs cannot be met through mainstream services.

Recommendation 1: Invest in foundational supports to bring fairness, balance and sustainability to the ecosystem supporting people with disability

🗍 Legislative change required

To develop the national architecture and strategy for foundational supports...

- Action 1.1: <u>National Cabinet</u> should agree to jointly design, fund and commission an expanded and coherent set of foundational disability supports outside individualised NDIS budgets.

- 🗍 Action 1.2: The <u>Department of Social Services</u>, with state and territory governments, should develop and implement a Foundational Supports Strategy.

To plan, fund and deliver general foundational supports...

- Action 1.3: <u>National Cabinet</u> should agree to jointly invest in and redesign information and advice and capacity building supports.

- Action 1.4: <u>National Cabinet</u> should agree to jointly invest in navigation support for people with disability outside the NDIS.

- Action 1.5: <u>National Cabinet</u> should agree to jointly invest in achieving nationally consistent access to individual disability advocacy services.

- Action 1.6: <u>All Australian governments</u> should fund systemic advocacy of LGBTIQA+SB people with disability to strengthen representation at all levels.

- Action 1.7: The <u>Department of Social Services</u> and the <u>National Disability Insurance Agency</u> should improve linkages between the NDIS, Disability Employment Services and related initiatives targeting improved employment outcomes for all people with disability, including NDIS participants.

- Action 1.8: <u>National Cabinet</u> should agree to jointly invest in a capacity building program for families and caregivers of children with development concerns and disability.

To fund and deliver targeted foundational supports...

- Action 1.9: <u>National Cabinet</u> should agree to jointly invest in state and territory home and community care support programs to provide additional support to people with disability outside the NDIS.

- Action 1.10: The <u>Department of Social Services,</u> with states and territories, should develop a nationally consistent approach for the delivery of aids and equipment outside the NDIS.

- Action 1.11: <u>National Cabinet</u> should agree to jointly invest in psychosocial supports outside the NDIS to assist people with severe and persistent mental ill-health currently unable to access supports.

- Action 1.12: <u>National Cabinet</u> should agree to jointly invest in early supports for children with emerging development concerns and disability.

- Action 1.13: <u>National Cabinet</u> should agree to jointly invest in programs and initiatives to support adolescents and young adults with disability aged 9 to 21 to prepare for and manage key life transition points such as secondary school, employment and living independently.

2.1. Foundational Supports – questions and answers

We recognise that foundational supports is a new concept proposed by the Review to bridge the gap between the availability of disability-specific supports available inside and outside the NDIS.

The questions and answers, below, have been put together to clarify what foundational supports are, who can access them and how they interact with other parts of the ecosystem of supports for people with disability – as well as guide the development of the Foundational Supports Statement and Strategy (see Action 1.1 and Action 1.2)

2.1.1. What are foundational supports and who can access them?

Foundational supports are disability-specific supports that are available for and benefit people with disability outside of NDIS individualised budgets.

Foundational supports should prioritise the support needs of the 2.5 million Australians with disability under 65, and where appropriate families and carers.

People with disability aged over 65

Foundational supports will need to work effectively with services and supports provided through the aged care system. But it should not replace those services.

People aged over 65 will likely benefit from some foundational supports, such as information and advice, but should receive most of their supports from the aged care system, or a combination of the NDIS and the aged care system.

Families and carers

Some supports funded under general foundational supports will be available for families and carers of people with disability. For example, information and advice supports. There will also be supports specifically for families and carers, including family capacity building supports.

General foundational supports

General foundational supports are disability-specific supports that are available for and benefit all people with disability under 65, and where appropriate families and carers.

Targeted foundational supports

Targeted foundational supports are for specific groups of people with disability outside the NDIS under 65 who are in most need of additional support.

People with disability may access supports from one or both foundational support streams, depending on their disability and their needs.

2.1.2. What types of foundational supports should be available?

General foundational supports

General foundational supports include:

- *Navigational supports* that help people with disability understand, find and access mainstream services, community supports and activities, foundational supports, and the NDIS. Navigators will also build the individual capacity of people with disability to determine their own goals and participate in their community. See Action 1.4 and Action 4.1.
- *Information and advice supports* including online and face-to-face support that help people with disability, families and carers make informed decisions and access appropriate supports. See Action 1.3.
- *Individual capacity building supports* that help people with disability build their skills, knowledge and confidence to participate in their community and be more independent, including self-advocacy, peer support and supported decision-making. See Action 1.3.
- *Family capacity building supports* that empower families and carers to exercise informed choice and control around supports for their child or family member and realise the vision of a valued and inclusive life. See Action 1.8.
- *Advocacy supports* that promote and protect human rights for people with disability, including resolving complex challenges that people are unlikely to resolve on their own and may need assistance with (does not include self-advocacy). See Action 1.5.
- *Disability employment supports* that help people with disability find and keep meaningful and long-term employment. Disability employment supports may also be accessed by some NDIS participants as part of NDIS individualised budgets. See Action 1.6.
- *Mainstream capability building supports* will work with mainstream services (such as health and education) within a defined geographic location to be more inclusive and accessible for people with disability. This includes training and education. Foundational supports will contribute towards mainstream capacity building. However, it is important to remember that these supports should complement and enhance not substitute or replace existing mainstream service responsibilities and investments from all governments. See Action 1.3.
- *Community capacity building supports* will work with community organisations and groups (such as sports and recreation clubs, local businesses) within a defined geographic location to be more inclusive and accessible for people with disability. Foundational supports will contribute to investment and effort towards community capacity building. It is important to remember that these supports should complement not substitute or replace existing responsibilities and investments from state, territory and local governments. See Action 1.3.

We recognise that further general foundational supports may be identified during the development of the Foundational Supports Strategy.

Targeted foundational supports

Targeted foundational supports should include:

- *Home and community care (HACC) supports* that help people with disability live independently in their home and community, including personal care and domestic assistance. These are primarily for people with less intensive supports needs, including people with chronic health related conditions. See Action 1.9.

- *Aids and equipment supports* that help people with disability live independently in their home and community. See Action 1.10.
- *Psychosocial support services* that support adults with psychosocial disability build their individual capacity, and support their personal recovery. See Action 1.11.
- *Early support services* for families and children with emerging developmental concerns closely linked and integrated with mainstream services. See Action 1.12.
- *Independence and transition supports* that support adolescents prepare for employment and independent living. See Action 1.13.

We are aware there is not comprehensive data about the needs of people with disability outside the scheme. To make sure emerging needs are addressed, we recognise that further targeted foundational supports may be identified over time.

2.1.3. How will people access foundational supports?

People with disability, families and carers should be able to easily find and access appropriate foundational supports in their community.

Access to foundational supports should be designed and delivered in a way that caters to the diverse needs of individuals and of particular community groups, including First Nations people with disability, people from a culturally or linguistically diverse background, people with disability who are LGBTIQA+SB, or those who live in rural or remote areas.

Some people with disability, families and carers will be able to access foundational supports directly without assistance. For example, information and advice through a website, or a peer support group or contacting an advocacy organisation through a local shop front or website.

There will also be many people with disability, families and carers who require support to find and access foundational supports.

Navigators should act as the central points of entry for linkages and referrals to foundational supports, mainstream services and community supports and activities for all people with disability (not just participants). Navigators must have the capability to:

- Support people with disability to determine their own goals and participate in activities in their community
- Connects and link people with disability to mainstream services, community supports and activities as well as foundational supports
- Develop working relationships with mainstream services, community organisations and foundational support organisations.

National Disability Insurance Agency (NDIA) staff, including regional offices and the call centre, must also have the capability and knowledge to link people with disability, families and carers to foundational supports in their community and/or their Navigator. The NDIA has an established brand and presence, so it is likely that people with disability will also continue to seek support from the NDIA (regardless of the role of Navigators) to find and access support in their communities.

People with disability, families and carers may also be referred or connected to foundational supports by informal supports (such as family and friends), mainstream service providers (such as general practitioners, schools or maternal child health centres), community organisations, or organisations delivering other foundational supports (for example a Disability Representative and Carer Organisation may refer someone to a peer support group).

2.1.4. Why are foundational supports important?

Foundational supports should enable all people with disability to access the right supports, at the right time and in the right place. They should support and enable genuine community participation and inclusion in community and ensure people have what they need to reach their full potential and lead lives of their choosing.

General foundational supports

General foundational supports should ensure:

- People with disability, families and carers have access to quality, accurate and up to date information and advice to make informed decisions and choices
- Families and carers have the capacity and capability to support their family member to achieve their goals, and to be included in their community
- People with disability have the skills and ability to self-advocate, make important decisions and contribute to their community
- People with disability have greater social and economic independence, resilience and support through peer networks
- People with disability can access and benefit from the same services and participate in the same activities as everyone else.

Targeted foundational supports

Targeted foundational supports should ensure people with disability outside the NDIS, particularly children, have access to early intervention supports, at the earliest stage possible. This should produce the best outcomes and reduce the current and future impact of disability.

Governments should adequately invest and prioritise targeted foundational supports. These supports should be:

- Centred on the needs of people with disability, families and carers
- Focused on early intervention, prevention, or low intensity care
- Planned, funded and delivered jointly by all governments, to ensure supports can be scaled nationally and adapted locally to meet community needs
- Evidence-based and outcomes focused
- Built upon and leveraging existing supports across services systems, including the NDIS and mainstream services (where possible).

2.1.5. How do foundational supports interact with supports as part of a NDIS individualised budgets?

General foundational supports

General foundational supports should be complementary and distinct from supports funded as part of a NDIS individualised budgets.

All people with disability under 65, regardless of whether they have a NDIS individualised budgets should be able to access and benefit from general foundational supports.

Targeted foundational supports

Targeted foundational supports are for specific groups of people with disability aged under 65 who are not eligible for the NDIS and whose needs cannot be met by mainstream systems. They therefore require additional disability specific support.

Targeted foundational supports are similar to the types of supports that are available as part of NDIS individualised budgets. What is different is how much support will be provided, the period of time support should be provided for, and how it will be delivered.

For example, children with disability outside the NDIS and inside the NDIS can both access early support services, such as capacity-building supports. However, the level of support delivered through targeted foundational supports should be less intensive for children outside the NDIS and may be provided for a shorter period of time.

2.1.6. What is the distinction between mainstream services and foundational supports?

Mainstream services

All Australians rely on mainstream services such as hospitals, schools, justice system and public transport. There are also a wide range of programs and activities based in the community that Australians take part in, such as those run by community groups, non-government organisations, sporting clubs, local councils, employers, church groups and charities.

Ensuring people with disability can use the same services and participate in the same activities as everyone else is a fundamental human right under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).[7]

This means all government services and community organisations have a responsibility to be inclusive and accessible and meet the needs of people with disability. In addition to these responsibilities, organisations are also required to make reasonable adjustments to practices, policies or processes that minimise participation barriers for people with disability (as required under *the Disability Discrimination Act 1992* and relevant state and territory legislation).

Mainstream service providers are responsible for making reasonable adjustments so that:

- People with disability can effectively navigate and access individual mainstream services, such as the health and justice systems

- People with disability can access appropriate supports and participate in mainstream services, such as schools and early childhood centres.

Foundational supports

Foundational supports are disability-specific supports that build on top of inclusive and accessible mainstream services and communities.

Foundational supports should not be used to fulfil mainstream service obligations or replace mainstream services. Nor should they be used to fill gaps in services.

Foundational supports recognise that even after mainstream services and supports fulfil their service obligations, some people with disability will still have additional disability specific needs. Foundational supports can help by:

- Providing time limited funding to build the capacity of mainstream service providers and communities to be more inclusive and accessible for people with disability. Funding should be allocated for activities that go beyond mainstream service responsibilities and reasonable adjustment obligations (see Action 1.3).
- Supporting people with disability find and connect with mainstream services and community supports and activities (see Actions 1.3 and 1.4).
- Building the skills and connections of people with disability to participate in in their community (see Action 1.3).

2.2. There is a lack of support outside the NDIS for people with disability because of underfunding and no clear strategy

2.2.1. All people with disability have the right to access and benefit from foundational supports

Foundational supports are a vital component of the support system for people with disability, families and carers. Foundational supports are about making sure people with disability, can access the right supports, at the right time and place, whether or not they have a NDIS individualised budget. They also align with the Productivity Commission report in 2011, which envisaged that the NDIS would be built on a firm foundation of community-based supports.

The fairness, trust, and sustainability of the NDIS depends on the delivery of community-wide foundational supports for all people with disability.

Data from the 2018 Survey of Disability, Ageing and Carers showed about 1 in 5 (18 per cent), or 4.4 million, Australians live with disability. Approximately 2.5 million Australians with disability are under the age of 65, including 1.4 million people with disability who need assistance with daily living activities.[8] As at 30 June 2023, more than 610,000 people with disability have NDIS individualised budgets, including 583,000 under the age of 65.[9] This means there are approximately 800,000 people under 65 with disability who rely on supports outside of the NDIS to meet their daily living support needs.

The NDIS was not designed to support all people with disability – only those with the highest support needs. Most people with disability are not in the NDIS – and never will be – because their disability support needs are not sufficiently high to require individualised funding. For this to be true three things must also happen:

- Community attitudes must continue to change.
- Mainstream services must become more inclusive and accessible.
- Foundational supports must be much more widely available.

Without these changes people with disability outside the scheme will continue to experience discrimination, disadvantage and poorer social and economic outcomes.

General foundational supports such as information and advice, individual capacity building and navigational support should be available to all Australians with disability under 65. In addition to general foundational supports, more targeted foundational supports should be available for particular groups of people with disability who are most in need of additional support and do not have a NDIS individualised budget.

Targeted foundational supports include things like HACC supports for people with chronic health related conditions and other disabilities, early supports for children with development concerns and psychosocial support services.

There could also be circumstances when it is appropriate to jointly commission targeted foundational supports and supports available as part of NDIS individualised budgets, such as aids and equipment. Doing this could increase governments' purchasing power and deliver more cost-effective supports for people with disability.

Our concept of foundational supports has built upon the 2011 Productivity Commission report into Disability Care and Support and the Information, Linkages and Capacity Building Policy (ILC) Framework

There are currently a range of disability-specific supports that are available for people with disability, families and carers outside of NDIS individualised budgets. These supports have a long history in the disability support system, both before and after the introduction of the NDIS. They were described as 'Tier 2' supports by the Productivity Commission in their 2011 report. They were renamed in 2015 to the Information, Linkages and Capacity Building (ILC) program.[10]

While the Productivity Commission report provided a useful framework for how the different "tiers" of supports should interact as a joined-up system for people with disability, limited detail was provided on how Tier 2 supports should be managed and what supports should be prioritised, beyond information, linkages and referrals, local area coordination and HACC programs.

Figure 1: The three tiers of the NDIS (2009 population estimates)

The three tiers of the National Disability Insurance Scheme
2009 population estimates

Tier 1

Social participation, minimising the impact of disability, insurance (target=Australian population) **22.5 million**

Tier 2

Information, referral, web services, and community engagement. Target = all people with disabilities **(4 million)** and their primary carers **(800 000)**

Tier 3

People receiving funding support from the NDIS Target = people aged O to the pension age with sufficient needs for disability support and early intervention

(3a) People with intellectual, physical, sensory, or psychiatric disabilities who have significantly reduced functioning (330 000)

(3b) Early intervention group (80 000)

(3c) Others optimally supported (unknown, but modest)

(3d) Funded support for some carers

Total = around 410 000

While this lack of specificity in relation to Tier 2 supports is understandable, given the focus of the Productivity Commission report on the NDIS, it has contributed to the current challenges.

In 2015, Commonwealth, state and territory disability ministers agreed to rename Tier 2 as ILC. All governments agreed to the ILC Policy Framework (ILC Framework) to support implementation. The ILC Framework described five activity streams:

- Information, linkages and referral
- Capacity building for mainstream services
- Community awareness and capacity building
- Individual capacity building
- Local Area Coordination.

The first four activity streams have been implemented as part of the ILC grants program, firstly managed by the NDIA and currently by the Department of Social Services (DSS). Local area coordination has been implemented separately by the NDIA as part of the Partners in the Community Program.

While well intentioned, the ILC grants program and local area coordination have not delivered on their ambition of delivering adequate supports that benefit all Australians with disability, families and carers. More detailed information on the history and effectiveness of the ILC grants program and local area coordination is outlined in Section 2.3.

We recommend an integrated and graduated model of **foundational supports**, which is bigger in scale, broader in scope and has a longer-term focus than ILC.

We propose to build on the original idea of tier 2 and ILC through an improved framework of foundational supports. The term foundational supports best describes what they are - the supports that offer people with disability a foundation to live a good life and be included in the community. Foundational supports are essential to a complete disability support ecosystem. One which ensures people with disability, inside and outside the NDIS, can access the right support at the right time and place.

This expanded foundational supports model would move Australia from a fragmented and sometimes contested disability support ecosystem characterised by a severe 'cliff' between the supports available inside and outside the NDIS, to a more connected, balanced and fair ecosystem (Figure 2).

Figure 2: Vision for an integrated, graduated model of supports for all people with disability
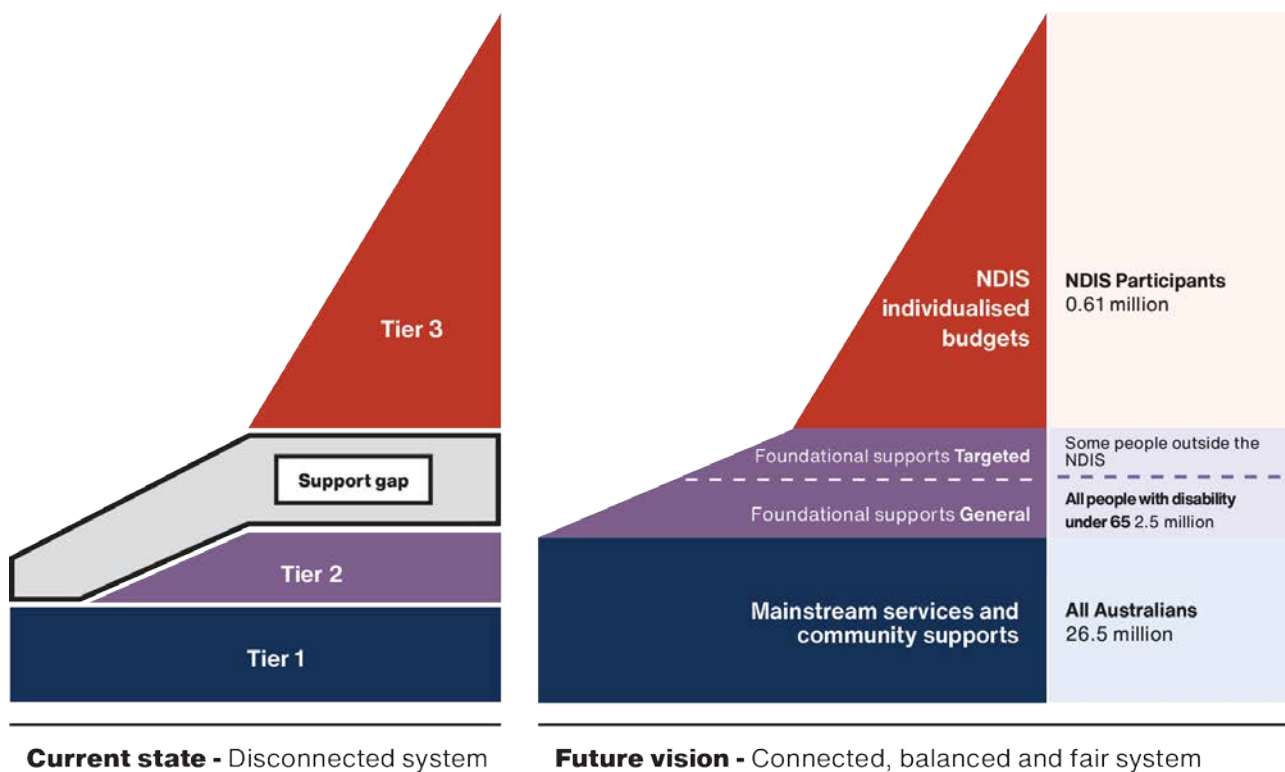
2.2.2. People with disability outside the NDIS are missing out on the support they need

There is not enough specialist disability support, such as assistance with daily living and evidence-based therapies, for people with disability outside the NDIS. We can see this in available data, academic research, and evidence received by the Review. We have found this to be particularly evident for children, adults with psychosocial disability and adults with lower intensity supports needs, including people with chronic health conditions.

The current situation results in poor outcomes for people with disability and is deeply inequitable. More people seek support from the NDIS, even though other models of support may be more efficient, effective and appropriate, increasing financial pressure on the Scheme.

> *"The overwhelming majority of Australians with disability are reliant on programs outside of the NDIS to access supports and services... Many people living with disability struggle to access the support and services they need and must either self-fund or go without." – MS Australia* [11]

Quantitative evidence

There is currently insufficient data on the needs of people with disability outside the NDIS. Despite initiatives to strengthen data collection and reporting across the disability landscape, including Australia's Disability Strategy (ADS), the focus remains disproportionately on the NDIS and NDIS participants. In time this should be improved through the National Disability Data Asset and the National Disability Research Partnership, which are new and important initiatives However, the limited data and research that is available indicates substantial support gaps for people with disability outside the NDIS.

Data from the most recent Survey of Disability, Ageing and Carers (SDAC) conducted in 2018 indicates that a significant number of people with disability have unmet support needs. Of all people with disability under 65 who require assistance, 43 per cent or around 600,000 reported that their assistance with daily living needs were only partly met or not met at all.[12] While the continued transition to the NDIS will have likely improved this statistic, evidence from other sources suggests a significant gap remains.

NDIS access data is a valuable source to better understand how many people currently receive support from the NDIS and how many people have not met NDIS eligibility. NDIS access data shows that people with certain disability types, such as chronic health related conditions and psychosocial disability, have higher ineligibility rates and numbers than others. Other groups, particularly children, access the NDIS at a higher rate than expected. Both these cases point to a lack of support outside the NDIS that people are trying to meet through the NDIS.

Children

As at June 2023 over half of participants, or just over 313,000 people, were children aged between 0 and 18.[13] In addition, 8 per cent of children aged 5 to 7 were NDIS participants and 11 per cent of 5 to 7 year old boys and 5 per cent of 5 to 7 year old girls were NDIS participants.[14] Figure 3 shows how this compares to other age groups with children having the highest rate of eligibility of any age group.

Up to June 2023, 98 per cent of children aged 0 to 6 and 89 per cent of children aged 7 to 14 who have tested access have been deemed eligible for the NDIS.[15] The number and proportion of children receiving NDIS individualised funded packages is much greater than the 2.9 per cent of 0 to 14 year olds the Productivity Commission forecast in 2011 and a much greater proportion of the population compared to other age groups.[16]

While there are several reasons for this, including the historical underdiagnoses of childhood conditions, insufficient support outside the NDIS for children can also lead people to access the NDIS. We explore this further in Sections 2.10 and 3.8.

Figure 3: NDIS access decisions by age[17]
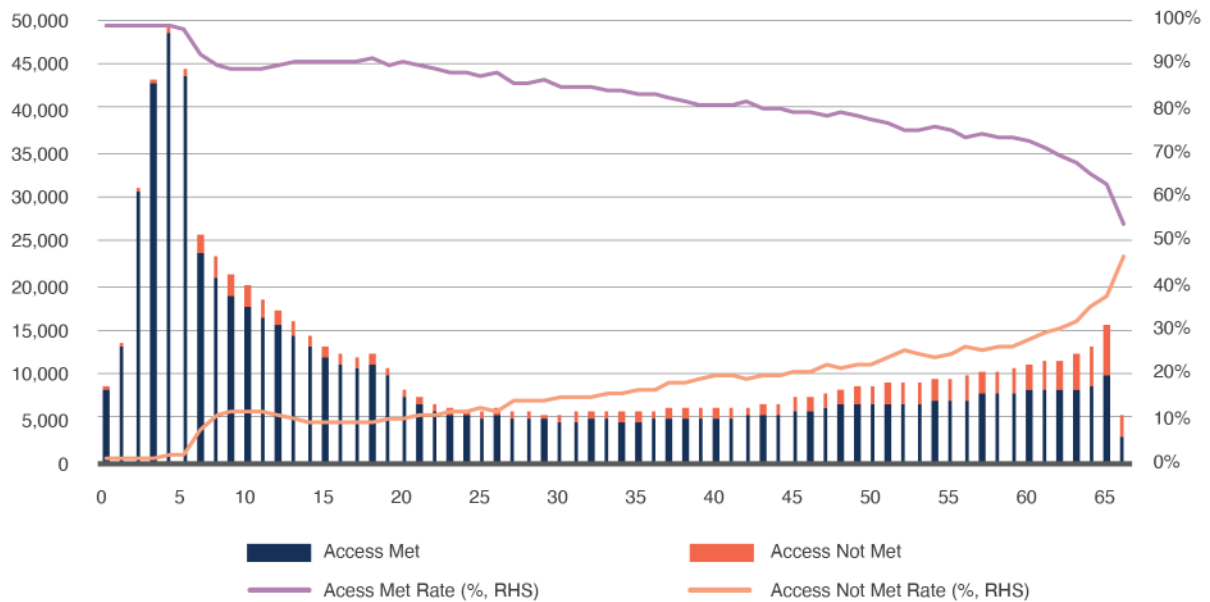
Psychosocial

From 2013 to the end of 2022, approximately 108,000 people have not been found eligible for the NDIS, including around 77,000 adults and around 23,000 children.[18] Figure 4 shows how NDIS access rates and numbers vary between disability groups, with some groups being found ineligible at a higher rate than others.

Figure 4: NDIS access decisions by primary disability[19]
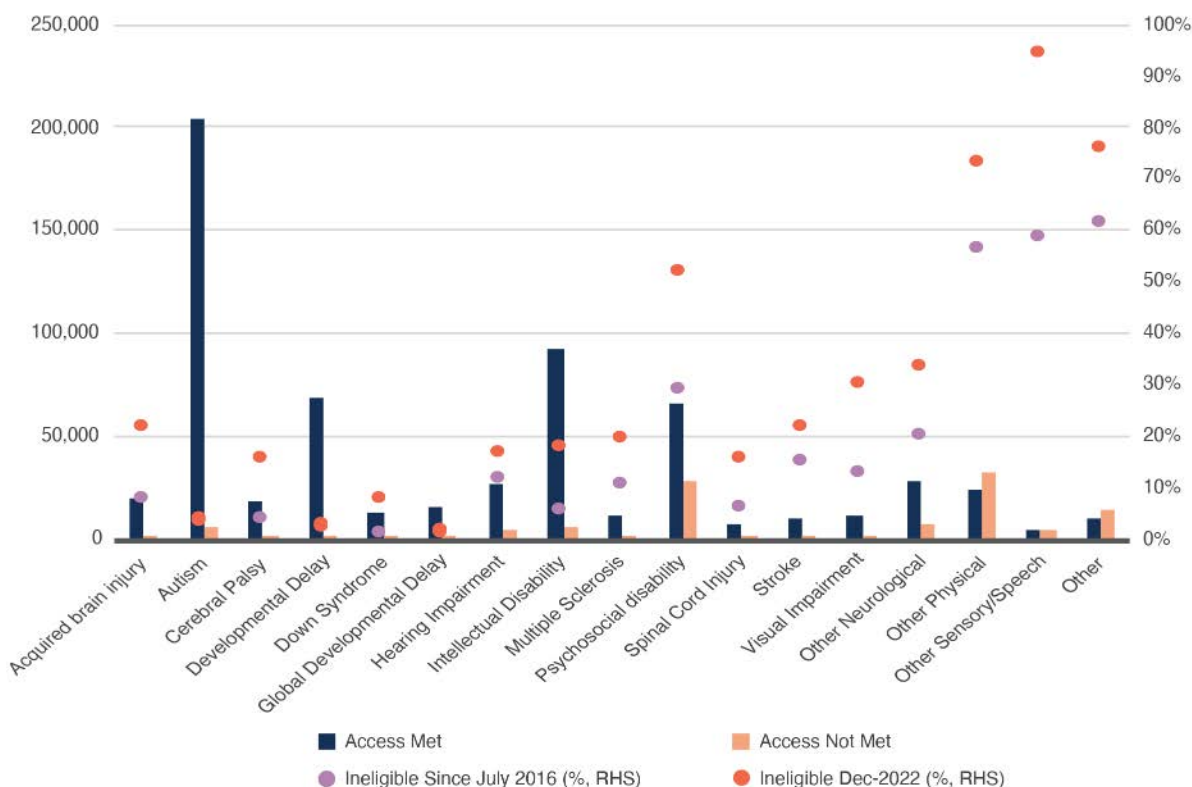
In total 27,000 people, or a quarter of all those ineligible for the NDIS, had a primary disability of psychosocial.[20] People with psychosocial disability also have one of the highest rates of ineligibility for the NDIS, alongside people with chronic health conditions.

In the last quarter of 2022, 49 per cent of people with a primary psychosocial disability who applied for the NDIS were deemed ineligible.[21] The suggestion that high rates of ineligibility are driven by a lack of available support outside the NDIS is supported by the Productivity Commission's 2020 estimate that around 154,000 people with severe and persistent mental illness were unable to access appropriate psychosocial support services outside the NDIS.[22] These figures suggest there is significant unmet disability support need for adults with a psychosocial disability. We explore the experience of people with psychosocial disability in and outside the NDIS further in Chapter 2.

Chronic health conditions

Adults with chronic health conditions make up over half of all Australians who have not met access for the NDIS. Since the scheme's inception, as of September 2022, around 56,000 people with chronic health conditions as a primary condition have applied and been deemed ineligible.[23] People with primary chronic health conditions have significantly higher levels of the highest level of ineligibility, compared to other disability types. In the September quarter of 2022, for people aged 35 or older at time of access decision, 75 per cent of people with chronic health related conditions who applied were deemed ineligible for the NDIS – this is compared to 27 per cent for all scheme

applicants without a chronic health condition.[24] Again, we can infer from this significant unmet disability support needs.

Data on repeat access requests also sheds light on demand for supports outside the NDIS. The NDIS assessment process can be challenged and often is. Applicants may also renew an access request. As of March 2023, around 36,500 participants have entered the scheme after initially being found ineligible.[25] It is legitimate for applicants to retest their eligibility or to challenge an access not met decision – for example, evidence requirements may be unclear or misinterpreted during someone's first application. The persistence to retest may also be evidence alternative supports are not available or that their support needs are not being met while remaining outside the NDIS. As one might expect, this occurs most frequently as a proportion of those disability groups who face the highest ineligibility rates, represented below in Figure 5.

Figure 5: Participants who were eligible to join the scheme after an initial unsuccessful access decision (% of total)[26]
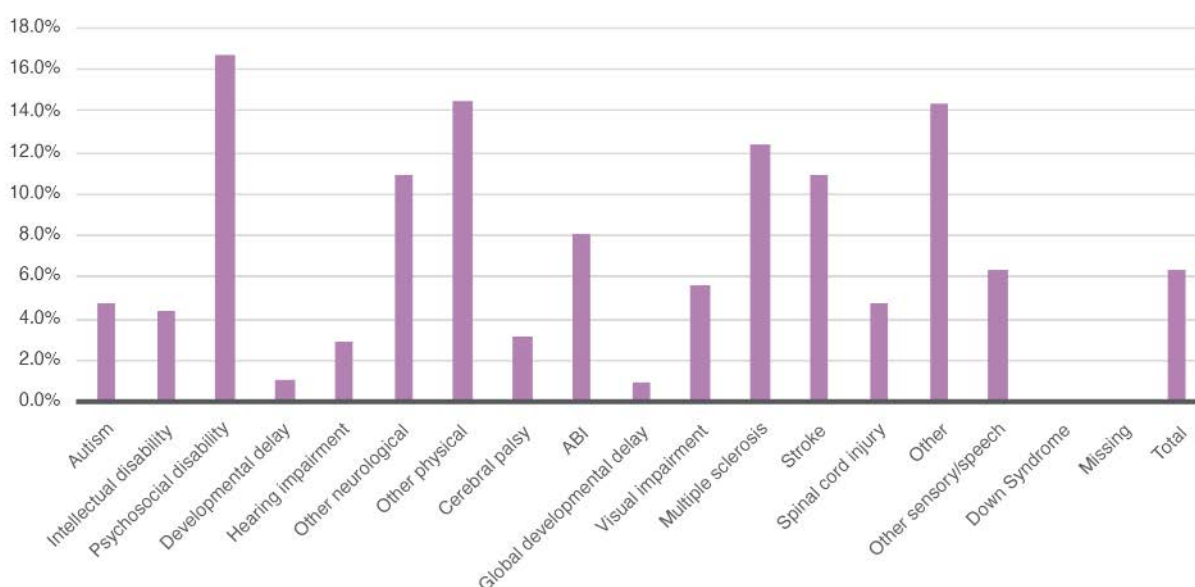
Overall, this data highlights the lack of available and appropriate support for some people with disability outside the NDIS.

Academic research

The lack of available and appropriate supports outside the NDIS was highlighted in the Melbourne Disability Institute's 2022 research paper, 'the Tier 2 tipping point: access to support for working-age Australians without individual NDIS funding'.[27] The research found that:

- 90 per cent of survey respondents (people with disability and families and carers) believe current supports and services outside the NDIS are inadequate in meeting the needs of people with disability
- There is a significant gap between the promoted availability and accessibility of support and services to people with disability who are not NDIS participants, and people's experiences of attempting to find and use them

- Being in or out of the NDIS has a considerable financial and personal impact on people with disability and their families
- Support promised under 'Tier 2' in the original design of the NDIS has not been delivered.[28]

This research drew on the feedback and perspectives of people with disability aged 18 to 64 in Victoria, South Australia and Tasmania who are not NDIS participants, families and carers who care for people disability who are not NDIS participants and representatives from the disability sector.

In addition, research conducted in 2023 by the Disability Advocacy Network of Australia (DANA) with people with disability and disability advocates has highlighted the lack of available and affordable supports outside the NDIS and the negative impact the transition to the NDIS has had on some groups. The research found that:

- Approximately 87 per cent of survey respondents believe there is a lack of any support without a current NDIS plan
- Approximately 73 per cent believe the cost of getting support can vary a lot and services may not be available
- Over 70 per cent of survey respondents said there is less support available outside the NDIS since the transition to the NDIS.[29]

Evidence received by the NDIS Review

As part of the NDIS Review we have listened to people with disability inside and outside the NDIS, their families and carers, the disability sector, researchers, and governments to understand the adequacy and effectiveness of supports outside the NDIS.

As part of submissions received, interviews, and workshops we found that:[30]

- **Availability** – there is a lack of available and appropriate foundational supports that people with disability can access within their community

    *"Outside the NDIS there is very little available to support children with disability and their families both in terms of specialist disability supports, and mainstream services."
    – Healthy Trajectories Child and Youth Disability Research Hub [31]*

    "The failure of tier two has left significant support gaps and seen the closure of many community services. More and more organisations are only interested in offering services to those with NDIS plans and certain line items in those plans." – Carer and NGO [32]

- **Navigation and awareness** – even when supports may be available, they are challenging to identify and find for people with disability, families and carers

    "There was a home and community program in my community – but nobody told me about it. I could have got help earlier if I had of known about it." – Person with disability" [33]

- **Affordability** – appropriate supports may be available, but they are often expensive. People with disability have to self-fund or go without. This raises issues of fairness.

    "Without access to the NDIS, people with communication disabilities are extremely limited in avenues for speech pathology support. Whilst there has been much discussion of Tier 2 supports, in practice these are restricted and many supports – such as independent community hubs for assistive technology – have been shut down." – Speech Pathology Australia[34]

2.2.3. Current funding levels for foundational supports are insufficient to meet the needs of people with disability

All Australian governments continue to increase their contributions to the NDIS each year. Continued commitment reflects the strong ongoing political and public support for the scheme.

Over the past decade, funding for disability services has increased from $8.2 billion in 2012-13 to $31.3 billion in 2021-22.[35] This has been life changing for hundreds of thousands of people with disability who have received support from the NDIS, including many who have received support for the first time.

However, what we have been told and what we have observed is a disability support system which is out of balance.

Governments have come to rely on the NDIS as the dominant, and in some cases only, source of supports for people with disability.

This has resulted in an unbalanced disability support system that relies too heavily on the NDIS at the expense of an inclusive, accessible and thriving broader disability support ecosystem of mainstream and foundational supports.

Almost all disability funding is provided through individualised budgets. In 2021-22, supports within the NDIS made up more than 93 per cent of all disability funding, as outlined in Figure 6. According to the Productivity Commission's Report on Government Services (RoGS) in 2021-22 annual expenditure on the NDIS was approximately $29 billion, and non-NDIS contributions (including foundational supports) accounted for approximately $1.75 billion.[36]

Figure 6: NDIS contributions and direct disability service delivery spend[37]
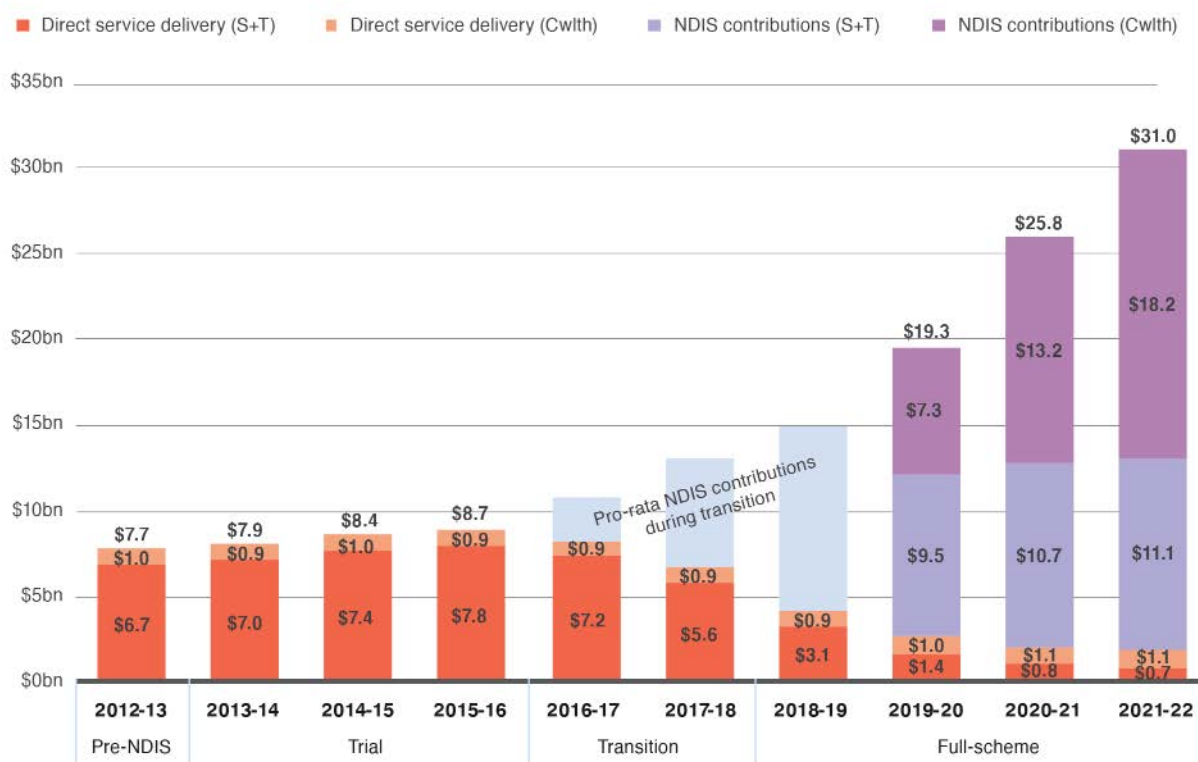
While the RoGS provides a useful reference point for approximate expenditure on foundational supports, there are definitional issues and inconsistencies, driven by legacy reporting mechanisms and an inconsistent approach in how and what the Australian Government and states and territories report.

To supplement the RoGS, we also analysed more detailed data on expenditure provided by Australian, state and territory governments, as well as existing publicly available data sources (data from Western Australia has not been received). Data quality limitations and inconsistencies across jurisdictions has made it challenging to gain an accurate and complete picture of current investment in foundational supports.

We estimate that Australian, state and territory governments spend at least $2.67 billion per annum on foundational supports (disability specific supports available outside of a NDIS individualised budget).[38] Key insights from this data include:

- The Australian Government contributes approximately $1.76 billion of total expenditure. The Disability Employment Services program accounts for approximately 76 per cent of this expenditure.
- States and territory governments contribute approximately $909 million of total expenditure.
- The Australian Government, states and territories jointly invest in information and advice and capacity building supports (individual, mainstream and community) as part of the ILC program, and navigational supports (as part of the Partners in the Community Program).[39]

- The most significant areas of expenditure from the Australian Government include Disability Employment Services, psychosocial support services and advocacy (the National Disability Advocacy Program). Other areas of expenditure include early support services and information and advice (the Disability and Carer Gateway).
- The most significant areas of expenditure from states and territory governments include psychosocial support services, HACC programs and advocacy. Other areas of expenditure include early support services and aids and equipment.
- Expenditure is largely uncoordinated and inconsistent across jurisdictions.
- There is variation between the expenditure data provided to the Review and the RoGS, presenting challenges in determining an accurate level of total investment program investment.

This analysis highlighted serious limitations with how data is collected and reported on with different interpretations surrounding the relationship between foundational supports, mainstream services and specialist supports as part of a NDIS individualised budget. For example, some programs and activities straddle mainstream services and individualised budgets, such as some supports provided in forensic disability services and out of home care. While others provide vital connections between mainstream services and foundational supports, such as Justice and Health Liaison Officers. Regardless of where they sit in the ecosystem, these programs and activities are essential to meeting the support needs of people with disability.

Critical to better defining foundational supports and addressing data quality limitations is a national strategy that clearly defines foundational supports across governments and guides how data is collected and reported for expenditure and outcomes. By doing so, governments could better understand where support gaps exist, what investment should be prioritised and how supports are improving the lives of people with disability, families and carers.

However, to be clear, while better data will provide more insight into the current gaps and challenges with foundational supports, it will not fix them on its own. It must also be coupled with sizeable increases in investment.

What does limited investment mean for people with disability?

A gap between the type and level of supports inside and outside the NDIS is to be expected, given this is an explicit design feature of the NDIS. That a gap exists isn't itself an issue. Average funding for people with an individualised budgets should be greater than people with disability who are not eligible for the NDIS. This reflects the higher support needs of NDIS participants. The issue is that the gap is too large and the funding outside the scheme is too low, leading to an unbalanced and unfair support system.

First, we know that people outside the NDIS are missing out on the supports they need. These supports do not exist, or are not provided at an adequate level, because they are not funded at an adequate level. This leads to poorer social and economic outcomes for people with disability.

Second, we know that if supports aren't available outside the scheme, people will seek to access them inside the scheme instead. Consequently, more people seek support from the NDIS, even

when the NDIS may not be the most appropriate and effective support. This puts significant financial stress on the Scheme. As the Melbourne Disability Institute noted:

> *"Tier 2 of the NDIS is an under-examined, high-risk and complex policy environment that is shaping the life course of some of Australia's most marginalised citizens, with far-reaching social and economic costs. Without intervention, it will generate significant future increases in NDIS costs" – Melbourne Disability Institute* [40]

This suggests a cycle where the more funding that goes to the NDIS, the greater the gap between the types of supports available inside and outside the NDIS grows. Inadequate supports outside the NDIS may mean that someone's quality of life may worsen and their health may deteriorate to such a point where individualised supports under the NDIS are then required to lead an ordinary life. Therefore, the greater this gap grows, the greater the incentive or need to try and enter the NDIS, and the less investment in disability support governments will be willing to provide outside the NDIS.

This cycle has two consequences. There can be poor social and economic outcomes for people outside the scheme. And there is a financial cost as allowing people's health and disability to deteriorate will eventually increase the cost of meeting their needs within the NDIS.

2.2.4. There is limited accountability and transparency for investment in foundational supports and outcomes delivered

Since the establishment of the NDIS there has been a lack of strategy and clarity on definitions, priorities and responsibilities for disability support outside of the NDIS.

The Productivity Commission noted the need to resolve uncertainty about responsibilities for disability services outside the NDIS as part of its review of NDIS Costs (2017) and the National Disability Agreement (2019). However, based on the evidence presented to the Review, little has changed.

> *"Tier 2 of the NDIS is intended to help all people with disability, and their families and carers, access services and support beyond the scheme itself … [But] Our research reveals complex, disconnected and incomplete markets of services and supports being navigated by people with disability and their families and carers; a service ecosystem riddled with inconsistent costs, eligibility criteria, information, priorities and availability of services; and heavy reliance on informal support networks and personal resources among people with disability without NDIS funding." – Melbourne Disability Institute* [41]

There is no clear vision for what foundational supports should achieve and why it's important for people with disability and the sustainability of the NDIS. As a result, there is no common understanding of what is required, what role governments should play and where investment should be directed.

While governments continue to invest in foundational supports to varying degrees, there is limited planning, coordination and collaboration across jurisdictions. This has created inconsistencies in the types of foundational supports available across Australia (for example HACC programs and advocacy) and has made it challenging for people with disability to navigate the system and find the most appropriate support.[42]

There are several factors that have contributed to a lack of strategy and investment in the delivery of foundational supports:

- Differing views about the split of responsibilities between levels of government in providing disability supports outside the NDIS.
- An expectation from some governments that ILC and local area coordination programs would be sufficient to meet the needs of people outside the NDIS.
- The absence of a clear and coordinated strategy across governments that sets a vision and identifies investment priorities.
- Limited accountability and transparency measures to track and report on government investment and outcomes.
- No clear governance arrangements to support decision-making, collaboration and planning

Without change, there will continue to be poor outcomes for people with disability and growing NDIS sustainability issues.[43]

2.2.5. Foundational supports need increased investment and a clear strategy to ensure they are planned, coordinated and delivered effectively across jurisdictions

We are proposing three major reforms to address the underinvestment in foundational supports and ensure a more balanced and equitable support system:

- **Greater funding**: ensure funding for foundational supports is equitable and reduces the gap between what is available inside and outside the scheme.
- **Expansion of supports**: increase the type and level of foundational supports available for people with disability, and make sure foundational supports are available broadly and consistently.
- **Improved design and delivery**: improve how foundational supports are designed, delivered and funded, striking the right balance between innovation and short-term priorities and the long-term sustainability and success of the community and disability sector.

These reforms should be guided by a Foundational Support Strategy (Strategy) to ensure good planning, coordination and accountability, with suitable governance to track and measure outcomes. The Strategy should be jointly designed, funded, and commissioned by the Australian and state and territory governments.

A significant increase in investment in foundational supports is urgently required to tackle the unfair gap between the supports inside and outside the NDIS – and ensure people with disability

can access timely and appropriate support they need to live more independently and thrive in their community.

Increased investment will deliver better social and economic outcomes, including:

- Access to early intervention supports and low intensity care, at the earliest stage possible, reducing the current and future impact of a person's disability on their functional capacity and participation.
- Access to care and support that improves mental health and wellbeing.
- Access to independent information and advice to make informed decisions and choice.
- Support to ensure participation and genuine inclusion in community.
- Support to self-advocate, lead and contribute to community.
- Greater social and economic independence, resilience and choice and control.
- Families and carers have the capacity and resources to support their family and loved ones with disability.

Greater investment in foundational supports will not only deliver better outcomes for people with disability, families and carers, but also contribute to the sustainability of the NDIS. First, by ensuring people with disability can use the same services and participate in the same activities as everyone else. This should reduce the reliance on individualised funded supports in the NDIS over time. Second, ensuring people with disability can access appropriate foundational supports at the right time and right place will help people to be both more independent and connected, and reduce the need for more intensive supports over time.

Critical to guiding investment in foundational support is the development of the Strategy. The Strategy should aim to:

- Ensure effective planning, coordination, and accountability for investment and outcomes delivered by foundational supports.
- Reduce the 'cliff' between those inside and outside the NDIS, by promoting equitable, efficient, and effective supports for all people with disability.
- Ensure only high-quality foundational supports are invested in, by being explicitly evidence-based and outcomes focused.
- Ensure community buy-in, by prioritising activities led by people with disability.
- Prioritise support where it is need most, by being place-based and responsive to community needs.
- Engage and get 'buy-in' from local governments, given their vital role in ensuring that local communities are inclusive (and noting that local governments are signatories to the ADS).
- Support a sustainable and effective NDIS.

Incentives and structures should also be put in place to make sure the Strategy can live up to its ambitions. This includes:

- An outcomes framework which measures, tracks and reports on investment and outcomes across foundational supports. The framework should be supported by a detailed mapping of

current foundational supports across jurisdictions. The framework should be aligned with reporting obligations under the Disability Outcomes Council (see Action 20.5) and the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- An implementation plan which should outline when and to what degree priority actions should occur and markers for what success looks like relative to the desired outcomes. The implementation plan should be reported against publicly on a yearly basis, measuring progress, and complement reporting obligations under the Disability Outcomes Council (see Action 20.5) and the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- Governance mechanisms including a dedicated forum representing the community to provide public accountability, feedback and advice on the adequacy of implementation, and a senior responsible person in the Australian Government for the oversight of the Strategy across governments. Foundational supports governance mechanisms should align with proposed ecosystem governance reforms (see Recommendation 20).

2.2.6. Action & Implementation Details

Action 1.1: National Cabinet should agree to jointly design, fund and commission an expanded and coherent set of foundational disability supports outside individualised NDIS budgets.

This should follow the recommended principles for joint funding (see Action 20.2) and be formally agreed as part of the Disability Intergovernmental Agreement (see Action 20.1). As an immediate step, National Cabinet should develop and release a Foundational Supports Statement of Intent (Statement). The Statement should define foundational supports through two streams of activity (general and targeted), including the new Navigator function (see Recommendation 4). The Statement should represent a commitment from all governments to all people with disability that foundational supports will be developed and funded as a critical part of an effective and sustainable disability ecosystem.

Implementation detail:

The Statement should articulate the vision, desired outcomes and in-principle investment priorities. Developing and releasing the Statement should be an immediately priority. It can then guide the development of the Foundational Support Strategy (the Strategy) (see Action 1.2). The Strategy should build on the Statement and provide more detailed information on how foundational supports be planned, coordinated and across jurisdictions.

The Statement should also:

- Define the vision for foundational supports. For example, "A fair, connected and outcomes focused support system that ensures all people with disability can access the right supports, at the right time and place to achieve their potential".
- Outline key outcomes expected from foundational supports, for people with disability, governments and the wider community.

- Agree in-principle to increased investment in foundational supports, including identified investment priorities for specific support types and population groups.
- Detail how all governments will work together to ensure foundational supports meet current and emerging needs of people with disability.

Action 1.2: The Department of Social Services, with state and territory governments, should develop and implement a Foundational Supports Strategy.

The Foundational Supports Strategy (the Strategy) should provide a clear plan to make foundational supports more widely available and more outcomes focused. The Strategy should be a schedule to a new Disability Intergovernmental Agreement (see Action 20.1). The Strategy should be focused on improving the planning, coordination, implementation, and accountability of foundational supports across jurisdictions. Foundational supports should be co-funded, and co-commissioned across all jurisdictions and reflect deep engagement with people with disability, their families and carers. The Strategy will incorporate, redesign and expand the current Information, Linkages and Capacity Building program so that it is more strategic and long-term while also promoting innovation in community development (see Action 1.3). The Strategy should be supported by a dedicated advisory group made up of Disability Representative Organisations and people with disability.

Implementation detail:

To guide investment and delivery of foundational disability supports, the Strategy should:

- Define the vision for foundational supports. For example, "A fair, connected and outcomes focused support system that ensures all people with disability can access the right supports, at the right time and place to achieve their potential".
- Establish clear principles to guide investment. For example, generally targeted towards people outside the NDIS, focused on early intervention and prevention, evidenced based and outcomes focused, placed-based and responsive to community needs and support a sustainable and effective NDIS.
- Describe the differences between foundational supports, mainstream services and NDIS individualised budgets and their responsibilities.
- Outline how people with disability, families and carers will find and access foundational supports. This should include the role of Navigators, the National Disability Insurance Agency, mainstream services, community organisations and other foundational support organisations play.
- Establish a mechanism for the ongoing identification and monitoring of unmet need for support for people with disability, particularly outside the NDIS, and developing approaches for responding to that need.

- Ensure an appropriate regulatory approach to quality and safeguarding, in line with the recommendations of this Review (see Actions 17.1 and 19.2).

- Establish an outcomes framework which measures, tracks and publicly reports on investment and outcomes across foundational supports. The framework should be supported by a detailed mapping of current foundational supports across jurisdictions. The framework should be aligned with reporting obligations under the Disability Outcomes Council (see Action 20.5) and the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- Include an implementation plan which details priority actions and investment required by governments, with defined timeframes, to realise the vision and outcomes of the Strategy. The implementation plan should be reported against publicly on a yearly basis and complement reporting obligations under the Disability Outcomes Council (see Action 20.5) and the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- Be supported by robust governance arrangements that ensure that implementation of the Strategy occurs to a high standard, and those responsible for creating foundational supports are accountable for achieving Strategy outcomes. It should also ensure engagement between all governments and the people they represent is constructive. This could include:

  - The Disability Reform Ministerial Council monitoring and overseeing the Strategy and implementation plan, including a minimum of one update per year on progress and outcomes.

  - A dedicated advisory group made up of Disability Representative Organisations and people with disability. The group should provide public feedback and advice every two to three years on the adequacy of the Strategy and its implementation. The group should be representative of the community using and engaging with foundational, including representation from intersectional groups, including First Nations people, culturally and linguistically diverse, women and LGBTIQA+SB.

- Appoint a senior responsible person within the Australian Government with appropriately resourced supporting functions, for the oversight of the Strategy across governments.

- Conduct a detailed review and evaluation of the Strategy within five years of commencement.

2.3. Delivery and funding approaches for information and advice, capacity building and navigational supports have not been effective

2.3.1. The Information, Linkages and Capacity Building program and local area coordination were intended to build the capacity and skills of people with disability

Understanding the history of the ILC program is critical to improving the future design and delivery of information and advice, capacity building and navigational supports for people with disability, families and carers.

In July 2015 all governments agreed to the ILC Framework to support the implementation of ILC. The ILC Framework described five activity streams that would be delivered:[44]

- **Information, Linkages and Referral**: connecting people with disability, their families and carers with appropriate disability, community and mainstream supports
- **Capacity building for mainstream services**: building the capacity of mainstream service providers (such as health and education providers) to meet their obligations and make them more inclusive and accessible for people with disability
- **Community awareness and capacity building**: supporting organisations (such as not for profits, local councils, businesses) and people within communities to be inclusive of people with disability and understand the needs of families and carers
- **Individual capacity building**: building the capacity of people with disability through a range of activities, including peer support, supported decision-making and self-advocacy, as well as one-off, low level or episodic supports with a focus on preventative intervention
- **Local area coordination**: connecting across each of the streams of ILC to provide support to all people with disability, regardless of whether they have an individualised budget.

The first four activity streams above have been implemented as the ILC grants program, currently managed by the Department of Social Services (previously managed by the NDIA between 2016 and 2020). Local area coordination has been implemented separately by the NDIA as part of the Partners in the Community Program.

In 2016 the ILC Commissioning Framework[45] was developed by the NDIA to implement the ILC Framework. The ILC Commissioning Framework was informed by nation-wide consultations with people with disability, families and carers, and the disability sector. It outlined the role of ILC in the NDIS, the outcomes expected, how activities would be selected and funded, how performance would be measured and managed and transition arrangements for state and territory governments. The NDIA also developed an outcomes framework to measure the impact of activities funded by ILC.

Between 2017 and 2018 state and territory governments worked in collaboration with the NDIA to progressively transition to the NDIS and ILC. ILC funding was allocated for delivery of supports in each state and territory through a combination of competitive grant rounds and transitional funding agreements. ILC funding was intended to be allocated through a range of commissioning

approaches, however, due to administrative and operational barriers the NDIA was unable to allocate funding outside of grants.

In 2018 the NDIA released the ILC Investment Strategy (2018 – 2022) to outline how ILC would be delivered and funded across four program areas.[46]

Figure 7: ILC activity streams corresponding to ILC programs

ILC activity streams	ILC programs
Information, Linkages and Referrals	National Information Program
Individual Capacity Building	Individual Capacity Building
Community Awareness and Capacity Building	Economic and Community Participation
Mainstream Capacity Building	Mainstream Capacity Building

Following the release of the ILC Investment Strategy a series of grant rounds were undertaken across the four ILC programs in 2019 and 2020. In October 2020, the ILC grants program transferred from the NDIA to DSS.

In 2021 the Centre for Social Impact and Swinburne University of Technology conducted a review of the ILC program, which analysed gaps and unmet need across the program.[47] This review highlighted the importance of ILC funded activities, but also the significant limitations and inefficiencies in strategy, funding approaches and program design. More detailed information on the findings of this review are discussed in Section 2.3.3.

In 2022 funding for 389 existing ILC projects, due to expire between June 2022 and February 2023, was extended until 30 June 2024. These projects had been successful in grant rounds held between 2019 and 2020.

In 2023 grant rounds were undertaken across the Individual Capacity Building and Social and Community Participation programs with funding of $90 million over three years and $50 million over two years respectively.

The total annual funding for ILC amounts to approximately $135 million per annum.[48]

Figure 8: Approximate spread of funding across ILC programs

ILC programs	Funding amount and proportion	Grant number and proportion
National Information Program	• Approximately $21.0 million per annum • 15.6% of average total ILC funding	• 38 grants • 6.6% of total grants
Individual Capacity Building	• Approximately $60.8 million per annum • 45.0% of average total ILC funding	• 248 grants • 43.1% of total grants
Economic and Community Participation	• Approximately $42.1 million per annum • 31.2% of average total ILC funding	• 261 grants • 45.3% of total grants
Mainstream Capacity Building	• Approximately $11.1 million per annum • 8.3% of average total ILC funding	• 29 grants • 5.0% of total grants

2.3.2. Information and advice, capacity building and navigational supports are key to better social and economic outcomes for people with disability

Well designed, delivered and funded information and advice supports are essential for people with disability, families and carers. These supports lead to people with disability:

- Accessing high quality, accessible, relevant and easy to understand information.
- Having better knowledge and understanding about disability and where to find support from mainstream, community and foundational supports.
- Having greater trust, connections and usage of mainstream services and community supports and activities.
- Making informed decisions and choices.

We have heard from people with disability, families and carers about the importance of quality, trusted, accurate and localised information and advice supports.

> *"Providing accessible information and resources that are tailored to the specific needs of individuals is crucial. This ensures that they have access to relevant information, guidance and support. This can involve creating easy-to-understand materials, developing digital resources and disseminating community-specific information." – Person with disability and provider* [49]

> *"We heard in many of our consultations that where people get information from is important. Information from some sources like peer support groups or advocacy organisations is seen as being more reliable or trustworthy than information from other sources." – Down Syndrome Australia* [50]

Well designed, delivered and funded individual capacity building supports, such as self-advocacy, peer support and supported-decision making are esssential for people with disability. These supports lead to people with disability:

- Having skills and ability to self-advocate, lead and contribute to their community.
- Having greater social and economic independence, resilience and choice and control.
- Accessing and benefiting from the same services and participating in the same activities as everyone else.

Section 2.3.2 focuses on the importance of individual capacity building supports for people with disability. For specific information on family capacity building see Action 1.8.

Currently under the ILC program there is limited guidance regarding what individual capacity building is – and what activities should be prioritised. The Model of Citizenhood Support, developed by JFA Purple Orange, provides a useful framework for categorising individual capacity building supports according to types of capital:[51]

- Personal capital: related to belief in self, personal agency and aspirations
- Knowledge capital: related to information and skills
- Material capital: related to tangible physical/material resource
- Social capital: related to connectivity with other people

Individual capacity building supports are critical for all people with disability whether they are in the NDIS or not. They are particularly important for people with an intellectual disability who have historically limited opportunities to develop skills and even fewer opportunities to exercise them. Without appropriate investment in individual capacity building supports, like self-advocacy, peer support and supported decision making, many people with disability won't have the support they need to be connected in their communities and be empowered to make decisions.

> *"The NDIS is for worst-case scenario. Wouldn't it make sense to give someone a little bit of help, before they get to a worse scenario and need more intensive support." – Person with disability [52]*

> *"If you give us a little bit of support we won't fall through the cracks" – Person with disability [53]*

Investment in self-advocacy, peer support and supported decision making as part of foundational supports should be complemented by reforms that ensure NDIS participants, including those with complex needs receive tailored advice and decision-making support (see Actions 5.1 and 5.5).

We heard from people with disability about the importance of peer support and self-advocacy in developing new skills and friendships, advocating for issues that matter most to them and providing meaningful employment.

> *"I should not be ashamed of my disability. Self-advocacy and peer support makes us strong. We can do so much" – Person with disability [54]*

"It brings [self-advocacy] us together and gives us power and a sense that we're not alone and can make change happen" – Person with disability [55]

"It is important that we have a voice. I'm more confident in myself speaking up on issues that matter to me" – Person with disability [56]

"It has provided me a normal wage and has made me feel valued" – Person with disability [57]

The importance of self-advocacy for people with disability, in particular people with an intellectual disability has also been highlighted by research conducted by the University of New South Wales. This research showed that self-advocacy leads to tangible improvements in people's health and well-being, including to:[58]

- Support better mental health, by improving people's self-esteem and confidence, reducing loneliness and isolation, and providing a new found sense of 'belonging'
- Help people make positive lifestyle changes to improve their physical health and supporting people to access healthcare
- Facilitate the development of new skills that people can draw upon in other parts of their life
- Empower people to 'speak up', to understand their rights and to have greater choice and control
- Support people to make significant changes in their lives, for example, in relation to housing or employment
- Help to build people's resilience and support people to act, particularly in the face of sustained experiences of bullying and harassment.

Well-designed, delivered and funded mainstream and community capacity building supports are essential for people with disability, families and carers. These supports lead to:

- People with disability using the same mainstream services, community supports and activities as everyone else
- Mainstream services and community supports and activities delivering services that are appropriate to needs of people with disability
- Mainstream services and communities becoming advocates and leaders in inclusive and accessible practices.

Well-designed, delivered and funded navigational supports are essential for people outside the NDIS. These supports lead to:

- People with disability accessing newly established and existing foundational supports in their local community
- People with disability finding and accessing the right support, at the right time and place across support systems, including mainstream services and community supports and activities
- People with disability building their capacity to determine their own goals and participate in the local community.

We provide more information on the importance of navigational supports for all people with disability as part of Recommendation 4.

2.3.3. The Information, Linkages and Capacity building Program and Local Area Coordinators have not been coordinated, funded or delivered effectively

The ILC program has played an important role in supporting many people with disability to access information and advice, building their individual capacity and advocating for issues that matter most to them. Without the ILC program many critical supports would not be available, including peer-support, self-advocacy and supported decision-making.

> *"ILC has been important in helping people develop new skills and advocate for issues that matter most to us" – Person with disability/organisation [59]*

However, the ILC program has not provided adequate and effective supports for people with disability and has not driven systemic change to support inclusive and accessible mainstream services and communities.

We have identified several critical factors that have limited the success of the ILC program. These are consistent with findings from the Swinburne University of Technology review[60] and have been informed by submissions from people with disability, families and carers, disability sector organisations, governments and other key stakeholders. The critical factors are:

- Context and strategy

  - The ILC grants program and Local Area Coordinators (LACs) have operated in a significantly different context than was expected when the ILC Framework was agreed in 2015. The ILC Framework expected LACs would support people with disability outside the NDIS including linking people to services or community activities. LACs were also expected to play a significant role in community capacity building. The diversion of LACs into planning limited their ability to perform these two key tasks. [61]

  - There was no holistic strategy beyond just the ILC program that articulated the broader role of ILC and its relationship with other initiatives.

- Funding amount and design

  - Investment in ILC never matched the ambition of the ILC Framework – which sought to benefit all Australians with disability, their families and carers.

  - Funding has been short term, project-based, fragmented and reliant almost entirely on time limited grants with a lack of alternative commissioning approaches.

  - Funding approaches have not adequately supported national, state and community based infrastructure to enable innovative practice and ensure service continuity.

  - Funding approaches have been too centralised and have not sufficiently balanced national priorities and a desire for consistency with a need for subsidiarity and local ownership and priorities.

- Funding has been uncoordinated and has been disconnected with broader disability investment and initiatives, including Partners in the Community, the Disability Gateway and Disability Representative and Carer Organisations.

- No funding has been allocated for time limited or episodic supports that focus on early intervention.

- Funding for mainstream service and community capacity-building has been project based and have been relatively small and unsuited to systemic change.[62]

- Program design

  - The National Information Program has paid limited attention to improving the availability and delivery of face-to-face information and advice at a state and local level, with a disproportionate focus on nationally consistent information delivered online.

  - The connection between the National Information Program and other information related initiatives, such as the Disability Gateway, is not clear, with confusion on how and where to find disability specific information.

  - The ILC has led to many community-based projects, but there has been a lack of nationally consistent practice and variable coverage across states and territories. There has not been a mechanism to bring organisations together to share best practice or lessons learnt.

  - Many of the mainstream capacity building and economic/social community participation programs have been project or organisation specific (for example one hospital or one sporting club) The projects have not focused on ways to leverage meaningful inclusion and accessibility across entire communities. Their impact has therefore been more limited. There has not been a mechanism to link projects or organisations together.

  - Local governments have not been engaged, notwithstanding their major role in promoting inclusion in local communities.

- Sector engagement and grant processes

  - A lack of transparency and clarity on timeframes for grant opportunities coupled with a complex grant process has created barriers for organisations (including disability representative and carer organisations) in preparing funding applications.

  - Limited face to face engagement to support organisations understand funding opportunities and to manage and report on projects effectively.

  - Limited opportunities for organisations to build their capability, share resources and collaborate across the sector, for example communities of practice.

    "The ILC grants approach is currently viewed as a 'piecemeal', 'scattergun' and patchy 'jigsaw' of funding that undermines the achievement of the ILC outcomes." – Centre for Social Impact, Swinburne University of Technology [63]

"There needs to be a better balance between short term and long-term funding, and between continuity and innovation" – Organisation [64]

"A big part of the missing puzzle (ILC), I believe, is engagement and support of mainstream and community organisations so that people with disability feel welcome, supported and valued – in sporting clubs, neighbourhood centres, community groups, and everywhere people gather to socialise, learn and grow." – Carer and NGO [65]

Local Area Coordination

LACs were intended to play a critical role in the success of the NDIS and the ILC program. It was envisaged LACs would provide assistance to all people with disability to connect into mainstream services and community activities. In addition, LACs would work with communities to make them more inclusive and accessible. This was based on the successes of LACs in Western Australia, where the model originated.

In recognition of LAC's role contributing to the ILC program, they were intended to be the NDIA's largest single investment in delivering ILC outcomes. As part of the initial LAC partner contracts, it was stipulated that LAC partners were expected to allocate 20 per cent of effort towards the delivery of ILC activities, including supporting people with disability outside the NDIS.[66] We understand that current LAC contracts place no requirements for these activities.

As a result, there has been minimal or no incentives or accountability mechanisms in place to ensure LAC partners prioritise ILC activities and support people outside the NDIS. In addition, the NDIA has faced caps on its resources. As a result, LACs have focused all or nearly all of their attention on planning and assisting NDIS participants' access supports.

We have consistently heard that local area coordination has not worked as intended and is not meeting the expectations of people with disability, families and carers. This is highlighted by the lack of support for people with disability outside the NDIS and the lack of attention on delivering mainstream and community capacity building and inclusion activities.

"LACs provide little or no help to people who are not funded by the NDIS" – Melbourne Disability Institute [67]

"There is a specific need for information about other supports available in community, for people not eligible for a NDIS support plan. This was an intended role for LACs that has not been delivered and the impact of this gap means that people with disability not eligible for NDIS are not getting the supports they need." – Queenslanders with Disability Network [68]

"LACs spend most of their time connecting people to the NDIS rather than to their local community and mainstream services. NDIS participants regularly tell us their LAC has limited knowledge of – or presence in – their local community." – JFA Purple Orange [69]

Despite the shortcomings of local area coordination, we have heard that some LAC providers have established dedicated community capacity building functions and resourcing.[70] However, to meet

the requirements of their contracts with the NDIA, LAC providers have still prioritised the needs of NDIS participants.

There are several factors that have limited the success of LACs, including:

* Constraints on the NDIA's resourcing and staffing meant LACs were primarily directed to supporting NDIS participants through planning and accessing related supports, at the expense of their originally intended functions[71]
* Limited accountability and reporting requirements to incentivise LACs to support non-participants and delivery of mainstream and community capacity building activities
* A lack of coordination and alignment between LACs and ILC funded organisations and activities
* Limited coverage of LACs beyond metropolitan areas and major regional centres
* Community capacity building activities have been focused on raising awareness, particularly awareness of the NDIS, rather than on building inclusive and accessible communities
* Some LAC providers have insufficient disability expertise and knowledge of the communities they support. LAC contracts were awarded to large community service organisations or for-profit businesses. In some cases, the LACs had no previous footprint in the regions where they were contracted to provide services.

2.3.4. Increased investment coupled with reforms to design and delivery are critical to improving the quality and availability of foundational supports

We recommend the following three reforms to address current limitations in the funding, design and delivery of the ILC program and maximise social and economic outcomes for people with disability:

* A dedicated information and advice and individual capacity building initiative
* A dedicated mainstream and community capacity building and planning initiative
* The delivery of navigational supports for all people with disability, including allocation of a dedicated resources for people outside the NDIS.

These reforms should be complemented by:

* The proposed establishment of a family capacity building program for families and caregivers of children with development concerns and disability (see Action 1.8). This program should ensure families have access to timely and appropriate supports, such as information and peer support so they can build the skills and confidence to support their child or loved ones. Supports provided as part of family capacity building program should not duplicate supports provided as part of information and advice and individual capacity building initiative.
* The progressive roll-out of alternative commissioning arrangements for both First Nations communities and remote communities, starting as soon as possible (see Action 14.1). As part of this reform, communities will have the ability to decide what supports most appropriately meet local needs, which may include information and advice and capacity building supports and other foundational supports.

Information and advice / individual capacity building

We recommend a dedicated information and advice and individual capacity building initiative that expands the support available and addresses limitations with the National Information Program and Individual Capacity Building programs funded through ILC.

There is strong evidence for the expansion of individual capacity building supports for people with disability. They deliver significant social and economic for benefits people with disability and are a cost-effective way to deliver support. It is estimated that current ILC individual capacity building projects support approximately 30,000 to 45,000 people with disability, at an approximate cost of $1,300 to $2,000 per person.[72]

Given the benefits of individual capacity building supports and the number of people with disability who could benefit from these activities, this level of coverage is inadequate. We estimate that for every additional $1 million in investment, an additional 375 to 700 people with disability will access support. As a priority, expanded supports could help some of the 800,000 people with disability who rely on help outside of the NDIS to meet their daily support needs.

The proposed expansion of supports aligns with what we have heard from people with disability, the sector and other key stakeholders, as well evidence from previous inquiries, including from the NDIS Independent Advisory Council in 2021. The NDIS Independent Advisory Council recommended ILC funding be equivalent to 1 per cent of scheme costs, which would have equated to approximately $350 million per year.[73]

A balance must also be struck between providing longer term funding and ensuring flexibility to respond to emerging needs or encourage innovation. Longer term funding is essential to ensure programs and activities are available when people need them and can establish themselves as trusted and reliable. It is also essential to the viability of organisations, particularly small organisations. At the same time there must be a stream of short-term funding available to encourage innovation and creativity and respond to emerging or changing needs.

The expansion and redesign of information and advice and individual capacity building supports should be focused on:

- Ensuring more people with disability, families and carers are connected and have the information and advice they need to make decisions and choices. Information and advice supports funded under this initiative should not duplicate information delivered as part of the proposed Family Capacity Building (see Action 1.8)
- Build the skills and capacity of more people with disability to live independently and participate in their communities. Capacity building supports for families and carers should be delivered as part of the proposed Family Capacity Building program (see Action 1.8).

Key to achieving these outcomes and addressing current limitations of the ILC program are:

- Significantly increasing total funding to be more reflective of the need for and importance of foundational supports for people with disability

- Encouraging consortia at a national and state level, where appropriate, to support consistency, quality and availability of supports for people with disability

- Shifting towards longer term funding and creating dedicated funding streams for:

  - National and state-wide supports and initiatives, such as the delivery of national or state-wide information and advice for a particular disability-type or a nationally consistent model for self-advocacy

  - Local, community-based supports, such as local peer support groups which should then include priority groups with little support such as women with an acquired brain injury

  - New and innovative projects that could be replicated, shared or scaled nationally, such as a new approach to supported decision-making or how information and advice is delivered in rural and remote communities.[74]

- Using multiple and varied funding approaches, beyond time-limited grants

- Deliberate market engagement, prior to funding rounds, with people with disability and the sector to more effectively identify and address support gaps and investment priority areas

- More clearly prioritising Disability Representative and Carer Organisations and priority individual capacity building supports, such as peer support, supported decision making and self-advocacy, in recognition of the importance and value of supports delivered by people with disability

- Simplifying and improving the application and funding process. This would include engagement with people with disability and the broader community sector, such as holding face to face workshops with people with disability and providing materials in Easy English and other languages to support organisations that work with culturally and linguistically diverse communities to apply and deliver activities.

Mainstream and community capacity building and planning

We recommend a dedicated mainstream and community capacity building and planning initiative to address current limitations with the Mainstream Capacity Building and Economic and Social/Community Participation programs funded under ILC.

In contrast to the information and advice and individual capacity building initiative, this initiative will not deliver direct support for people with disability. Instead, it will fund organisations within a particular geographic region to work with mainstream service providers, such as local hospitals and schools, and community organisations, such as sporting clubs and businesses, to make sure they are more inclusive and accessible for people with disability.

The initiative should focus on:

- Supporting people with disability to use and benefit from the same mainstream services, community supports and activities (such as sporting clubs, arts and recreation, religious and cultural groups) as everyone else.

- Building the capability of mainstream services and community organisations to become advocates and leaders in inclusive and accessible practices.

- Building a strong and constructive relationship with the NDIA and navigators – that support people with disability to be connected and linked to mainstream services and community activities and supports.
- Improving mainstream services and community supports to deliver services that are appropriate to needs of people with disability.
- Complementing, not substituting, current and future inclusion and accessibility initiatives from Australian Government, state and territory and local governments.
- Mapping and highlighting existing mainstream services and community supports and identifying gaps or inefficiencies.

Key to achieving these outcomes and addressing current limitations of the ILC program are:

- Significantly increasing total funding so that it is more reflective of community need and the importance of inclusive and accessible mainstream services and communities.
- Facilitating consortia and partnership between local governments, Disability Representative and Carer Organisations, community sector organisations and local grassroots organisations. This should improve nationally consistent practice while ensuring activities and supports are responsive to the needs of local communities.
- Ensuring state and territories play a more active role in how the program is planned, funded and delivered, and the program is complementary of existing investment from state, territory and local governments.
- Ensuring funding complements and does not replace or duplicate existing state, territory and local government investment or responsibilities.
- Shifting toward longer term funding that is reflective of the systemic and long-term nature of driving meaningful change in inclusive and accessible mainstream services and communities.
- Shifting toward funding selected organisations for a defined geographic region (such as a Local Government Area, Service Region or Primary Health Network), rather than project funding to make an individual mainstream service (such as a hospital) or community organisation (such as a single sporting club) more inclusive and accessible.

Navigation Function

We recommend a dedicated funding stream is provided to ensure people with disability outside the NDIS receive fair, adequate and appropriate navigational supports. The investment and approach for navigational supports for people outside the NDIS should be guided by a new dedicated navigation function (see Action 4.1).

This dedicated investment should build up over time and when fully implemented deliver in the order of 5 to 15 hours per year of navigational support for an estimated 300,000 to 500,000 people with disability outside the NDIS. The estimated number of people outside the NDIS likely to access navigational supports has been informed by:

- The total number of people with disability deemed ineligible since the scheme began – 108,000 as of end 2022[75]

- The approximate number of people with disability accessing Disability Employment Services - 280,000[76]
- The approximate number of people under 65 with disability who rely on supports outside of individualised budgets to meet their daily living support needs - 800,000.[77]

Appropriate and proportionate investment is critical to ensure people with disability outside the NDIS can access the right support at the right time and place across the support ecosystem. This includes accessing more widely available general and targeted foundational supports, such as individual capacity building supports, HACC, early support services and psychosocial support services.

Failure to provide adequate navigational supports could delay or prevent people with disability accessing the right support, such as early intervention supports for adults with a psychosocial disability or children with development delay. This could in turn have negative flow on impacts for health, social and economic outcomes for people with disability, families and carers.

This approach should:

- Ensure people with disability outside the NDIS receive adequate and effective navigational supports.
- Empower people with disability outside the NDIS to determine their own goals, make their own decisions and work towards achieving what is important to them.
- Support people with disability outside the NDIS understand, find and connect with supports across mainstream, community and foundational supports and participate in their local community.

Key to achieving these outcomes and addressing current limitations of the LAC program:

- Deliver tailored and proactive support for people with disability outside the NDIS – beyond those deemed ineligible for the scheme.
- Create financial and other incentives to ensure support for people with disability outside the NDIS is prioritised and maintained.
- Ensure successful organisations have a strong and complementary relationship with local mainstream services, community organisations and foundational supports providers.
- Ensure successful organisations are held accountable for time, resources dedicated and outcomes for people with disability outside the NDIS.

2.3.5. Action & Implementation Details

Action 1.3: National Cabinet should agree to jointly invest in and redesign information and advice and capacity building supports.

These services are currently delivered through the Information, Linkages and Capacity Building (ILC) program. Replacing the existing program with two new initiatives should improve the consistency, quality and coverage of information and advice and individual capacity building

supports at a national, state and local level. The emphasis should shift from one-off disconnected project-based funding to reliable and longer-term funding for organisations who deliver advice and capacity building support that is available to all people with disability.

Implementation detail:

Australian governments, through their Foundational Supports Statement of Intent, should commit to replacing the ILC program with two new initiatives:

- Initiative one: Information and advice and individual capacity building
- Initiative two: Mainstream and community capacity building and planning.

Australian governments should commit additional funding towards these new initiatives. Funding should grow over time as this element of the Foundational Supports Strategy is implemented in full. This investment would be in addition to current investment (which is in the form of ILC program funding) and should then be indexed to maintain its value in real terms from year to year.

Initiative one: Information and advice and individual capacity building

The Australian Government with states and territories should establish and administer a new initiative for the delivery of national, state and local information and advice, and individual capacity building supports.

The initiative should:

- Ensure people with disability, families and carers are connected and have the information and advice they need to make decisions and exercise choice and control
- Improve the availability and accessibility of quality, independent and trustworthy information at a national, state and local level
- Improve and simplify how information and advice is coordinated across information systems, including the NDIS, Disability Gateway, mainstream services and individual disability specific information services
- Build the skills and capacity of people with disability to live independently and participate in their communities
- Support national, state and local coverage and best practice in priority activity areas, including self-advocacy, peer support and supported decision-making. In delivering this, consideration should be given to Actions 5.1 – 5.5
- Increase the availability of localised community based individual capacity building activities for people with disability. Program coordination should facilitate and support nationally consistent approaches and sharing of best practice, while ensuring local activities respond to local needs.

The following should occur to support implementation:

- Ensure organisations funded under funding stream one and two (see below) receive long term funding, for between three and five years, and in some defined circumstances ongoing funding

- Prioritise Disability Representative and Carer Organisations and self-advocacy, peer support and supported decision-making supports and initiatives

- Establish three dedicated funding streams:

  - Funding stream one: for national and state wide supports and initiatives. This should support greater consistency, coverage and best practice at a national and state level, including for self-advocacy and peer support.

  - Funding stream two: for local supports and initiatives. This should be focused on addressing community level needs that complement existing national and state supports and initiatives.

  - Funding stream three: provides short term funding (up to 24 months) for innovative projects. This should be focused on supporting the trialling and testing of new and innovative approaches that address current or emerging areas of unmet needs, or proposals which could be replicated, shared or scaled nationally.

- Establish focus areas to determine funding priorities across the initiative. These could include:

  - Specialist or diagnostic expertise: supports that address specific needs of particular disability groups, including people with intellectual disability and people with psychosocial disability

  - Intersectional groups: supports that address the needs of First Nations people, culturally and linguistically diverse, women and LGBTIQA+SB communities and people with co-occurring conditions

  - Rural and remote communities: supports that address local needs and circumstances in rural and remote communities

  - People led activities: supports that are delivered by people with disability, for people with disability

- Facilitate consortia at a national and state level, including community and volunteer led organisations.

- Use multiple funding approaches, including program funding, grants, seed funding, procurements and open and targeted tenders.

- Conduct market sounding, prior to commencing funding rounds, with people with disability, the disability sector and other key stakeholders to gather information on support gaps and inform investment priority areas.

- Develop an outcomes framework that tracks, reports and measures outcomes for people with disability at a national, state and local level. The framework will be reported against

publicly on a yearly basis. The framework should be aligned with the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- Ensure the initiative complements proposed foundational supports reforms for people with psychosocial disability and families and carers (see Actions 1.11 and 1.8).
- Improve funding processes and engagement including:

  - Provide predictable timeframes for grants and provide reasonable lead times between current and future rounds. This will enable organisations run by people with disability and small organisations to have sufficient time to develop proposals and seek assistance if required.

  - Delivery of face-to-face engagement to support organisations understand funding timeframes and requirements and ask questions.

  - Make applying and reporting on initiatives easy to understand and accessible for people with disability, including exploring non-traditional ways to collect information on people led initiatives (such as interview or video applications or non-standard ways of reporting on outcomes such as videos).

Initiative two: Mainstream and Community Capacity Building and Planning

The Australian Government with states and territories should establish and administer a new initiative for the delivery of mainstream and community capacity building and planning supports.

The initiative should:

- Support people with disability to use and benefit from the same mainstream services, community supports and activities as everyone else
- Build the capability of mainstream services and community supports/activities to be more inclusive and accessible for people with disability
- Build the capability of mainstream services and communities to become advocates and leaders in inclusive and accessible practices
- Build a strong and constructive relationship with the National Disability Insurance Agency and navigators – that support people with disability to be connected and linked to mainstream and community services

  - Map existing mainstream services and community supports and identify gaps or inefficiencies - for example particular mainstream services that are not inclusive or accessible or opportunities for collaboration across mainstream and community organisations.

The following should occur to support implementation:

  - Ensure selected organisations are responsible for driving inclusion and accessibility across a defined geographic location, for example specific local government areas, state government regions, Primary Health Networks, or across areas assigned to navigators

- Ensure mainstream and community capacity building activities are time limited and do not lead to ongoing resourcing

- Ensure selected organisations receive longer term funding, up to three years

- Ensure activities to drive inclusive and accessible mainstream services and communities complement current and future initiatives from Australian government, state and territory and local governments - and do not substitute or replace effort which is the responsibility of all governments

- Work in partnership with navigators and selected organisations to deliver foundational supports, mainstream service providers and community organisations (see Action 4.1)

- Develop an outcomes framework that tracks, reports and measures inclusion and accessibility outcomes for people with disability at a national, state and local level. The framework will be reported against publicly on a yearly basis. The framework should be aligned with the recommended new Disability Supports Outcomes Framework (see Action 23.1).

Action 1.4: National Cabinet should agree to jointly invest in navigation support for people with disability outside the NDIS.

This should ensure people with disability outside the NDIS receive fair, adequate and appropriate navigation supports (see Recommendation 4). It should support people to determine their own goals, connect with mainstream services, community supports and foundational supports and participate in their community.

Implementation detail:

Australian Governments, through their Foundational Supports Statement of Intent, should commit to navigational supports for people outside the NDIS. The funding amount should build up over time and could aim to deliver approximately 5 to 15 hours per year of navigational support for an estimated 300,000 to 500,000 people with disability outside the NDIS.

The following should occur to support implementation:

- Establish financial and other incentives to ensure support for people with disability outside the NDIS is prioritised and maintained.
- Ensure successful organisations are held accountable for time and resources dedicated for people with disability outside the NDIS.
- Ensure successful organisations are held accountable for outcomes delivered for people with disability outside the NDIS. This should be aligned with reporting obligations under the Disability Outcomes Council (see Action 20.5) and the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- Ensures successful organisations have a strong and complementary relationship with local mainstream services, community organisations and foundational supports providers.

2.4. Disability advocacy is underfunded and disconnected across jurisdictions, leading to people with disability missing out on effective advocacy support

2.4.1. Disability advocacy is a shared responsibility across jurisdictions

The Australian Government and state and territory governments agreed to the National Disability Advocacy Framework 2023-2025 (Advocacy Framework) and the National Disability Advocacy Work Plan (Advocacy Work Plan). The Advocacy Framework and Work Plan committed governments to shared responsibility for disability advocacy and achieving an effective network of disability advocacy across Australia.[78]

There are a variety of types of disability advocacy currently delivered across jurisdictions, including (but not limited to):[79]

- **Individual advocacy** is a one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer, to prevent or address instances of unfair treatment, discrimination, exploitation or abuse.
- **Systemic advocacy** involves working for long-term social change to ensure the collective rights and interests of people with disability are served through legislation, policies and practices.
- **Self-advocacy** is undertaken by someone with disability who speaks up and represents themselves. Support and training for self-advocacy is available through community-based groups and is funded primarily through the ILC program.
- **Legal advocacy** upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect. It is distinct from legal aid and legal aid services.

Disability advocacy is funded primarily through the National Disability Advocacy Program, administered by DSS, and state and territory advocacy programs.

Based on estimates from DANA and data provided to the Review, it is estimated that between $60 million and $100 million per annum is spent on disability advocacy programs by all governments, including approximately $25 million per annum for the National Disability Advocacy Program.[80] However, limitations in data quality present challenges in drawing an accurate picture of how funding is spread across jurisdictions, issues, disability types and advocacy types.

2.4.2. Disability advocacy support is essential to promote, protect and defend the human rights of people with disability and delivers significant social and economic benefits

Throughout history, people with disability have experienced violence, abuse, neglect, exploitation, segregation and discrimination. Despite progress, many people with disability continue to face barriers, discrimination and abuse, preventing them from enjoying the same rights, opportunities and freedoms as other Australians.

Disability advocacy plays a critical role in promoting, protecting and defending the human rights of people with disability, including First Nations people, people with complex support needs and people with disability who interact with the justice system.

Disability advocacy also supports people with disability to achieve better social and economic outcomes, including: [81]

- Increased choice, control and wellbeing, and ability to exercise their right to make decisions, and be involved in decision-making processes that affect their lives.
- Increased participation in civil, economic, and cultural life.
- Being empowered to express their views on how supports and services can be designed and delivered to better meet their needs.
- Improved access and experiences with mainstream services, community activities and supports and disability supports (including the NDIS).

Disability advocacy also plays a critical role in supporting regulatory oversight and complaints functions of the NDIS Quality and Safeguards Commission, Public Advocates across the country and the ombudsman functions in government.

Investment in individual disability advocacy supports delivers significant economic benefits. This is achieved by contributing to greater economic participation for people with disability and reducing the operational costs and pressure on other government services, such as child protection, education and health care. As part of a 2017 cost benefit analysis by DANA, it was estimated that disability advocacy provides a benefit-cost ratio of 3.5:1 for each dollar spent. [82]

2.4.3. Current disability advocacy supports are insufficient to meet the growing needs of people with disability, leading to people slipping through the cracks

Evidence from DANA suggests that there is approximately twice as much demand for advocacy in comparison to supply. Based on current resources, advocacy organisations are unable to meet the support needs of all people with disability. [83]

> *"Advocacy organisations cannot service all the people seeking advocacy support with current resources ... This is a massive shortfall with serious flow-on effects for people with disability and for mainstream systems" – Disability Advocacy Network Australia* [84]

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) has also highlighted the inadequacy of current disability advocacy supports. [85] Based on independent analysis commissioned on the level of unmet need for disability

advocacy the Royal Commission has recommended the Australian Government commit additional funding for 2024-25 and 2025-26 of $16.6 million a year for the National Disability Advocacy Program and $20.3 million a year for the NDIS Appeals Program.[86]

We have also heard that current advocacy supports are inadequate to meet the needs of people with disability. This is driven by a combination of factors:

- Advocacy organisations are underfunded to meet the advocacy support needs of people with disability

   "I rely on others to advocate for me, mainly mum and dad, as it is almost impossible to get an advocate." – Participant [87]

   "There is no advocacy funding so people can have certainty what they should be getting from whom and to support them to receive this." Participant, carer and provider [88]

   "Adequate ongoing funding and resources must be provided for individual advocacy to ensure that advocates are available by phone, online or in-person to participants and anyone needing expert advice and assistance to exercise their rights regardless of their location or mode of communication." – People with Disability Australia [89]

- Advocacy resources being overwhelmed and consumed primarily by NDIS related matters. This means that advocacy organisations do not have adequate resources to support people with disability outside the NDIS.

   "Currently, the NDIS accounts for approximately 50% of the advocacy workload across all types of advocacy." – Disability Advocacy Network Australia [90]

   "NDIS applicants are not lawyers but are expected to navigate a complex legal system nonetheless, often without advocacy or appropriate representation – which seems highly disadvantageous, if not discriminatory." Person with disability [91]

- A lack of available and effective foundational supports, including navigational support, information and advice, put*s pressure on advocacy organisations to fill service gaps and directs organisations away from their core business.*

2.4.4. A coordinated approach and additional funding for disability advocacy should ensure people with disability have access to effective support

While disability advocacy is a shared responsibility of all governments, further work is still required to translate this into effective practice.

The Australian, state and territory governments continue to fund disability advocacy programs separately. They use different service and funding models, and there is no mechanism to identify service coverage or identify unmet need at a national, state or local level. As a result, many people

with disability are unable to access effective disability advocacy supports, limiting their ability to exercise choice and control on the issues that matter most to them and participate as equal members in the community.

The Advocacy Framework and Advocacy Work Plan are important steps in aligning advocacy strategy, funding and practice across jurisdictions. While also translating shared responsibility into practice that leads to more accessible and effective disability advocacy supports.

What we have heard from people with disability, families and carers and the disability sector has reiterated the importance of all governments accelerating priority work areas under the Advocacy Work plan, including:

- A detailed mapping of current advocacy services across jurisdictions to provide a clearer picture of the availability of services and service gaps.
- A review of existing funding arrangements across jurisdictions that determines how much additional funding is required to meet the growing demand, with a particular focus on individual advocacy.

2.4.5. Action & Implementation Details

Action 1.5: National Cabinet should agree to jointly invest in achieving nationally consistent access to individual disability advocacy services

To ensure people with disability have access to effective individual advocacy support there should be better coordination of funding and activities across the Australian Government National Disability Advocacy Program, and state and territory advocacy programs. Funding increases should have regards to the findings from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, and the National Disability Advocacy Framework and Disability Advocacy Work plan.

Implementation detail:

The Australian Government in collaboration with state and territory governments should undertake the following to inform funding increases:

- Complete a detailed mapping of current advocacy services across jurisdictions that gives a clearer picture of the availability of individual advocacy services and identifies where service gaps exist.
- Complete mapping of existing funding arrangements across jurisdictions. This should focus on the adequacy of existing funding, identify opportunities to better coordinate existing funding and determine how much additional funding is required to meet the growing demand for individual advocacy services, including legal advocacy.

2.5. Disability policy, practice and services need to better understand and respond to the needs of LGBTIQA+SB communities

2.5.1. The Disability Representative Organisations program is intended to provide systemic advocacy and representation for Australians with disability.

The Disability Representative Organisations (DRO) program, administered by DSS, is designed to build the capacity for all people, and their representative organisations, to have their views communicated to government, regardless of type of disability, gender, cultural background, age or membership.

Funding enables nominated peak bodies to provide systemic advocacy for Australians with disability to:

- Promote an understanding of the lives of people with disability
- Promote and protect the rights and dignity of people with disability
- Foster support for the participation of people with disability in all aspects of community life.

These peak bodies provide advice to government on breaking down barriers and improving social and economic participation and engage with a range of ministers and portfolios.

2.5.2. LGBTIQA+SB people with disability continue to experience discrimination and underrepresentation

LGBTIQA+SB people with disability experience intersection and multi-layered discrimination due to their diverse sexual orientations, gender identity and intersex status. Applying an intersectional lens at all levels is fundamental to developing a more inclusive society for LGBTIQA+SB people with disability.[92]

Gender and sexuality are core elements of identity that impact how people with disability experience all aspects of life, including their disability, diagnosis, interaction with government services (including the NDIS), disability services and supports and social and economic participation. While robust intersectional data is poor, anecdotally we know disability prevalence rates are high amongst LGBTIQA+SB communities. The 2014 ABS General Social Survey estimated that 30 per cent of people who identify as gay, lesbian, bisexual or 'other' have a disability.[93]

A study in the United Kingdom found that autistic people are 3 to 6 times more likely not to identify with the sex they were assigned to at birth.[94] In Australia, a recent study found that 22.5 per cent of trans-identifying people have an autism diagnosis, compared to 2.5 per cent of the Australian population.[95] Autism Spectrum Australia has also highlighted this same study estimates up to 25 per cent of gender diverse people may also be Autistic.[96]

Despite the high prevalence of disability among LGBTQIA+SB communities, they often feel invisible and underrepresented. Research by Deakin University found that "Current policy and practice guidelines on disability care and support in Australia do not adequately acknowledge the unique experiences of LGBTIQA+ people with disabilities, or outline actions and strategies to address specific support and care needs."[97]

We heard about how this exclusion impacts on LGBTIQA+SB people's autonomy, safety, help -seeking behaviours and ability to access supports.

> *"Many of these groups may not have access to documentation required to prove eligibility, including due to age, lack of access to healthcare and other service systems, disconnection from family or community, and migration or displacement." – Co-Group Feedback to the NDIS Review Panel (Appendix B)*

We also heard how services fail to recognise and respond to cultural, gender and sexuality diverse need incite fear and put LGBTIQA+SB people with disability at a greater risk of harm.

> *"Access to services to assist with navigating the NDIS process might be difficult due to homelessness, a lack of digital or English literacy, a lack of services in rural and remote areas, a lack of culturally safe services, or fear of harm or discrimination on the basis of sexual or gender identity, particularly in faith-based organisations." – Co-Group Feedback to the NDIS Review Panel (Appendix B)*

In 2022, a research report commissioned by the Disability Royal Commission found that over a 12 month period more than half (52.7 per cent) of young people with disability (aged 14-21) experienced verbal harassment or abuse due to their sexuality or gender identity (compared to 34.7 per cent of young people without a disability). The same survey also found 15 per cent had experienced physical harassment, double that of those without disability (7.5 per cent). Most alarming however is that almost one third (31.7 percent) of young people with disability had experienced sexual harassment due to their sexuality or gender identity.[98]

2.5.3. A lack of representation is having negative impacts on inclusion and participation for LGBTIAQ+SB communities

The lack of disability rights-based advocacy for LGBTIQA+SB communities was identified throughout the Disability Royal Commission and led to the recommendation for the inclusion of LGBTIQA+ people with disability as a priority work area for the Advocacy Work Plan.[99]

In 2020, the NDIA recognised the need to respond through the development of an initial NDIA LGBTIQA+ Strategy. However, more needs to be done to ensure that we understand the profile of this culturally, gender and sexually diverse community to facilitate sustainable, systemic change.

Systemic advocacy is critical to securing positive long-term changes that remove discriminatory barriers to ensure that the rights and interests of people with disability are upheld. There is no dedicated DRO for LGBTIQA+SB people with disability. This has left existing disability, community and health organisations with this additional responsibility, overstretching their capacity to ensure they effectively represent the needs of all their members.

> *"They (LGBTIQA+SB community members) come to us (existing Disabled Person's Organisation) for help. We barely have enough funding and staff to cover our current scope, but we stretch and try to include them as well otherwise who will?! But we don't*

have the capacity to give them the in-depth attention they deserve and need." – Consultation [100]

This has contributed to significant gaps in the ability of disability ecosystem to:[101]

- Understand the experiences of LGBTIQA+SB people with disability
- Provide clear channels for inclusive policy reform
- Facilitate connections and peer development for LGBTIQA+SB communities
- Facilitate meaningful research that involves LGBTIQA+SB people with disability at all stages
- Promote the importance of LGBTIQA+SB disability research, for example under the National Disability Research Partnership
- Develop and advise services and agencies on inclusive practices for LGBTIQA+SB people with disability
- Broadly share and meaningfully embed educational resources
- Provide opportunities to highlight the intersectional identities held by LGBTIQA+SB people with disability
- Provide training for NDIA staff on how to include and support LGBTIQA+SB people with disability
- Evaluate the impact of LGBTIQA+SB inclusive practices and policies.

LGBTIQA+SB people with disability face unique stressors due to their intersectional identity that require systemic representation. This includes increased experiences of violence, discrimination, expectations of stigma and concealment of their identities. These factors are linked to increased psychological distress which can exacerbate social isolation and impact socio-economic outcomes such as education attainment, employment and health.

The National LGBTI Health Alliance told the Disability Royal Commission that "When people are part of a stigmatised group which is not immediately apparent, they must decide whether to "display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where…" Often LGBTIQA+SB people with disability feel like they have too many things to disclose to have their needs met which makes them feel like a burden. This results in them often having to make a choice of disclosing disability or LGBTIQA+SB identity based on the priority of immediate need.[102]

In 2018, a La Trobe University report found that research, policy and practice on the health and wellbeing of LGBTIQA+SB people with disability is "fragmented" and "under-resourced," that LGBTIQA+SB people with disability face higher rates of discrimination and reduced service access, and greater restrictions on freedom of sexual expression. This can be compounded by the lack of professional training, attitudes and unwillingness among disability services and workers to address the sexual and gender identity rights of LGBTIQA+SB people with disability.[103]

These gaps in the education and representation of the lived experiences of LGBTIQA+SB people with disability at a systemic level reinforces attitudes of dismissal and complacency. This contributes to the delay of creating a safe and inclusive disability service sector and society for gender and sexually diverse people with disability.

2.5.4. First Nations gender and sexuality diverse people have distinct cultural identities

For First Nations gender and sexually diverse peoples, the compounding experiences of intersectional discrimination mean that tailored, culturally safe and inclusive representation that understands and reflects culturally specific models of gender, sexuality and disability is needed to adequately represent this cohort and ensure meaningful change. This is also true for those from culturally and linguistically diverse background and has been reflected in Action 1.6.

We have prioritised the need to recognise and prioritise the unique experience of First Nations people, adopting use of the LGBTIQA+SB acronym present in the Australian Government's Implementation Plan on Closing the Gap and the landmark Wiyi Yani U Thangani (Women's Voices) Report, popularised by the First Nations advocacy organisation 'Black Rainbow'.[104]

2.5.5. Reforms to the DRO program are required to ensure LGBTIQA+SB people with disability are adequately represented at all levels of society

Moving forward all Australian governments should ensure that systemic representation of LGBTIQA+SB people with disability (inclusive of First Nations intersections) are specifically funded and sustained to represent this culturally, gender and sexually diverse intersectional cohort.

2.5.6. Action & Implementation Details

Action 1.6: All Australian governments should fund systemic advocacy of LGBTIQA+SB people with disability to strengthen representation at all levels.

This requires a commitment to funding under the Department of Social Services Disability Representative Organisation (DRO) Program. Currently there are no Disability Representative Organisations in this area. This is to ensure systemic representations of this culturally, gender and sexually diverse community are rights-based, informed by the social model of disability and enable in-depth consideration, elevation and representation of these distinct and complex communities. The development of a tailored model to represent this intersectional cohort should be led by Disability Representative Organisations and LGBTIQA+SB peak bodies. Jurisdictions should also review their systemic advocacy funding arrangements to include supports for building capacity of systemic LGBTIQA+SB advocacy. Ongoing funding should enable equal representation of LGBTIQA+SB people relative to existing systemic advocacy efforts.

Implementation detail:

- The Australian Government should provide additional funding under the DRO program to ensure sustainable and dedicated systemic advocacy for the LGBTIQA+SB communities
- The Department of Social Services should partner with LGBTIQA+SB disability stakeholders to design an appropriate funding pathway for dedicated systemic advocacy that will build on

existing expertise to elevate the voices of gender and sexuality diverse peoples with disability

- Identified partners for design should include First Nations, culturally and linguistically diverse representatives as well as meaningful representation from the autistic community in recognition of the significant prevalence of gender diversity

- The Department of Social Services in partnership with key stakeholders should explore (at a minimum) the following options:

  - Option One: An open competitive grant round for delivery of dedicated systemic advocacy by an existing organisation and/or consortia (open grant round)

  - Option Two: The division of funds amongst existing DROs with demonstrated experience and understanding of the social model of disability and intersectionality and advocating for their LGBTIQA+SB community members (targeted grant round)

  - Option Three: The establishment of a standalone disability rights informed peak and/ or DRO (seed funding)

- The Department of Social Services should ensure that LGBTIQA+SB systemic advocacy representatives are appropriately recognised and funded through their activity work plan to:

  - Produce educational resources that build understanding of gender diversity and disability across disability policy, programs and services

  - Develop, promote and deliver targeted education and training within mainstream services to raise awareness around intersectional issues, discrimination and how to deliver inclusive services for LGBTIQA+SB communities

  - Work with the National Disability Insurance Agency (NDIA) to advance implementation of the NDIA LGBTIQA+ Strategy (2020), and identify any gaps for future prioritisation

  - Support state based DROs to build representation and inclusion of LGBTIQA+SB peoples into their advocacy

  - Identify and report research and data gaps to the National Disability Research Partnership, National Disability Data Asset and government to ensure appropriate prioritisation in future research funding and data development plans (see Action 23.5)

- The Department of Social Services, NDIA and the new National Disability Supports Quality and Safeguards Commission should work in partnership with LGBTQIA+SB systemic advocacy representatives and jurisdictional based organisation (where appropriate) to develop:

  - Dedicated resources for community to self-advocate for accessible and inclusive services

  - Dedicated training and resources for improving the capacity of service providers to provide quality responsive and safe services for LGBTQIA+SB communities.

- All state and territory governments should support existing jurisdictional disability peak organisations to design an appropriate funding pathway (with consideration to the above proposed options) for dedicated systemic advocacy of LGBTIQA+SB people with disability.
- All state and territory governments should review their existing systemic disability advocacy funding arrangements (with consideration to the above proposed options) to ensure that there are appropriate resources to support sustained systemic advocacy of LGBTIQA+SB people with disability in their jurisdiction.

2.6. The disability employment support system is fragmented and has failed to deliver desired employment outcomes for people with disability

Greater economic participation for people with disability is central to improving the lives of people with disability, families and carers and realising the vision of the NDIS.

We acknowledge the significant body of work already undertaken across governments to improve employment outcomes for people with disability, including the Disability Royal Commission, reforms to the Disability Employment Services program and the Employment White Paper.

We are seeking to build upon existing recommendations and reforms and highlight ways to ensure efforts to increase rates of employment of people with disability could be connected across the ecosystem, including with the NDIS.

2.6.1. Improving employment outcomes for people with disability delivers significant benefits to individuals, workplaces, the economy and the wider community

Employment provides people with disability with increased income and financial independence. It has important benefits for an individual's wellbeing, self-worth and connectedness. Improved employment outcomes can also reduce the need for income support and other supports over time, including the NDIS and foundational supports.

Employing people with disability also has significant benefits for workplaces and the economy:

- Research has shown that workers with disability have higher rates of retention, better attendance and fewer occupational health and safety incidents than those without a disability.[105]
- Research conducted by Deloitte in 2011 has shown that closing the gap between labour market participation rates and unemployment rates for people with and without disability by one-third could result in a cumulative $43 billion increase in Australia's gross domestic product over the next decade in real dollar terms.[106]

2.6.2. There are multiple strategies, programs and reviews focused on improving employment outcomes for people with disability

Employment is a key priority of the ADS. To support this priority area, in 2021 all governments developed the Employ My Ability – the Disability Employment Strategy.[107] Actions taken under Employ My Ability are listed as part of the Employment and Community Attitudes Targeted Action Plans under the ADS.

The NDIA has also developed the NDIS Participant Employment Strategy (2019 – 2022) which sets out the vision and plan for increasing employment outcomes for NDIS participants.[108]

There are multiple programs and supports across the ecosystem that are designed to support people with disability find and maintain employment, including (but not limited to):

- **Workforce Australia Employment Services (mainstream):** support all Australians find employment and develop job-ready skills. People with disability have the choice to access supports from Workforce Australia Employment Services providers or Disability Employment Service (DES) providers
- **The DES program (foundational):** is the primary government program to support people with disability prepare for, find and maintain employment. DES service providers support approximately 280,000 people with disability.[109]
- **NDIS individualised budgets (NDIS):** the NDIS can fund employment related supports for participants who need extra help to pursue their employment goals. These supports are usually greater than what may be reasonably provided by an employer or with the support of the DES program. Funding is primarily used to support approximately 20,000 NDIS participants work in Australian Disability Enterprises (ADEs) as of 1 July 2020.[110] This reveals a major gap in service provision to support NDIS participants into mainstream employment.
- **NDIS School Leaver Employment Supports (NDIS):** helps NDIS participants make the transition from school to work. Supports are available in the final years of high school and directly after leaving school.

There are several reviews and reforms underway to improve existing programs and employment outcomes for people with disability, this includes:

- **Disability Royal Commission** highlighted the need for reform across several areas, including: the design of the DES model, improved transparency and accountability for employment outcomes and strategies in the public sector and the transition to more inclusive employment options.
- **The DES program review:** the Australian Government is developing a new specialist disability employment services model to replace the current DES program. The current DES program has been extended until 30 June 2025.
- **The Employment White Paper** has provided a roadmap for Australia to build a bigger, better-trained and more productive workforce – to boost incomes and living standards and create more opportunities for more Australians, including people with disability.[111]

2.6.3. Despite considerable attention and investment in employment programs and supports, employment rates for people with disability remain unacceptable

Research from the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW) and others continue to highlight the lack of progress in employment outcomes for people with disability in Australia:

- In 2018, 53.4 per cent of people with disability aged 15 to 64 were in the labour force compared with 84.1 per cent of people without disability.[112] This gap of over 30 per cent remains largely unchanged since 2003.[113]
- In 2018, there was a higher unemployment rate for people with disability, at 10.3 per cent compared to 4.6 per cent of people without disability.[114]
- In 2022, young people with disability aged 15 to 24 were more than twice as likely to be unemployed (25 per cent) as those aged 25 to 64 (7.9 per cent) with disability.[115]
- In 2022, young people with disability aged 15 to 24 were more likely than people with disability of other ages to want to work more hours. 23 per cent (or 27,000) were underemployed, compared with 8.1 per cent (or 71,000) of those aged 25 to 64.[116]
- The unemployment gap between people with disability and people without disability has widened from 4.0 percentage points in 2012 to 4.7 percentage points in 2018.[117]
- Only 10 per cent of Australian Public Service employees identified as having an ongoing disability as part of the 2022 APS Employee Census.[118]

Research from Swinburne University of Technology has highlighted that people with intellectual disability continue to be disproportionately underrepresented in employment, with employment rates remaining largely unchanged for the last 20 years.[119]

- The employment rate for people with intellectual disability is 32 per cent.
- Only 29 per cent of people with intellectual disability aged over 25 who are NDIS participants are in paid employment. Of these, more than 77 per cent work in an ADE usually for below award wages.

In addition, Australia's employment rate for people with disability continues to lag behind the performance of Organization for Economic Cooperation and Development (OECD) countries. In 2017, Australia ranked 20 out of 27 OECD countries for employment rates for people with disability.[120]

Poor employment outcomes for people with disability has negative impacts for people with disability and the wider community. This includes exacerbating socio-economic disadvantage and preventing people with disability being able to access the care and support they need.

As highlighted by the ABS and AIHW people with disability have low levels of income and a greater reliance on government supports and payments, relative to the broader population:

- NDIS participants are generally overrepresented in lower income households.[121]
- 41 per cent of people with disability aged 15 to 64 have income from wages or salary, compared with 73 per cent without disability[122]

- In 2018, 44 per cent of people with disability aged 15 to 64 receive a government payment, compared with 12 per cent without disability.[123]

The combination of limited paid employment, lower incomes, reliance on government payments, as well as a lack of affordable supports outside the NDIS presents significant challenges to people with disability accessing the support they need. While these challenges affect all people with disability, the impact on people with disability who are not eligible for the NDIS is particularly acute.

We heard from those who are not eligible for the NDIS that they often have to self-fund or go without the support they need, which can have detrimental impacts for people with disability, their families and carers.

This evidence highlights the importance of:

- Increasing the availability and accessibility of foundational supports – so that all all people with disability, regardless of whether they have a NDIS individualised budgets or not, can access the right supports, at the right time and place, and can achieve their potential.
- Undertaking reforms to tackle key contributors of poverty – including increasing employment opportunities for people with disability.
- Identifying and supporting more innovative and inclusive approaches to shift the continual underrepresentation of people with disability in the workforce. This includes supporting people with disability start and manage social and microenterprises through their NDIS funding and other initiatives. It also includes strengthening the role of peer workers in delivering NDIS supports and foundational supports, like peer support and self-advocacy.

2.6.4. Current approaches to disability employment are disconnected and have not adequately improved employment outcomes for people with disability

We have consistently heard from people with disability, families and carers, the disability sector and other stakeholders that current approaches to disability employment are not working. Key themes that people have raised include:

- There isn't a coordinated approach across employment programs and initiatives, with a lack of clear and integrated pathways between DES, the NDIS and other employment related programs and initiatives.

  "Employment support for people with disabilities isn't working well. NDIS does not work well alongside DES, people fall through the gaps, and DES workers/organizations have been given little to no training about what NDIS can provide and how they can get the best outcomes (it's all about Centrelink and policing people's mutual obligations)." - Participant[124]

- There is a lack of appropriate support to find and maintain employment, including for young people transitioning from School Leaver Employment Supports to other employment supports.

- The current DES system does not provide adequate or effective support for people with disability to find a job, particularly for groups historically underrepresented in employment, such as people with an intellectual disability.

  "DES in the old system was set up to truly assist you to achieve employment goals. … The current DES system is a tick and flick and just focused on any job and they don't care if that's not what you want." - Participant, carer, provider[125]

- There is a lack of innovative or tailored practice to meet the supports need of people with disability.
- Not enough attention has been paid to making workplaces more inclusive and accessible for people with disability, with too much emphasis on supporting people with disability to become job-ready.
- While many workplaces are open to employing with disability, not enough take the next step. A 2017 survey of 1,200 businesses found 93 per cent of large businesses and 89 per cent of medium-sized businesses indicated openness to hiring people with disability, but only around a third of all businesses actually did so.[126]

2.6.5. A connected, innovative and long-term approach is required to bridge the gap between employment outcomes for people with disability and the broader Australian population

Research undertaken by the University of Melbourne, University of New South Wales and the Brotherhood of St Laurence has identified three interventions to increase economic participation for people with disability:[127]

- **Supply side interventions:** seek to build the capacity of people with disability to be job ready and find employment appropriate opportunities, as well as building the capacity of employers to be more inclusive and accessible for people with disability.
- **Demand-side interventions:** create work opportunities for people with disability, by facilitating new or existing roles that may otherwise not be available for people with disability. This could include supporting more innovative and inclusive approaches to employment, such as supporting people with disability establish and manage social and microenterprises, and strengthening the role of peer workers in delivering NDIS supports and foundational supports.
- **Bridging interventions**: match people with disability to appropriate work opportunities and provide support to both employers and people with disability to drive positive employment outcomes.

What we have heard from people with disability, families and carer and the disability sector has confirmed the importance of delivering these three interventions in parallel, and the need for governments to accelerate existing disability employment reforms.

Action 1.7: The Department of Social Services and the National Disability Insurance Agency should improve linkages between the NDIS, Disability Employment Services and related initiatives targeting improved employment outcomes for all people with disability, including NDIS participants.

This should address issues with how the systems work together identified in the 2021 Disability Employment Strategy. It should include a joint action plan linking different elements of the ecosystem that contribute to improved employment outcomes for people with disability, including initiatives that build employee confidence and capability to employ people with disability. A particular area that needs attention is promoting peer worker support in the NDIS. The action plan should be informed by recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the Disability Employment Services Program Review, the current NDIS Participant Employment Strategy and other related inquiries.

Implementation detail

The action plan should:

- Adopt a balanced combination of supply side, demand side and bridging interventions;
- Establish targeted and transparent actions that aim to increase economic participation for people with disability. Specific actions and interventions should be identified to ensure people with an intellectual disability are supported into employment. Establish specific and ambitious targets for disability employment in the public sector, including for people with an intellectual disability. This should have regard to current Australian Government, state and territory government targets
- Identify and support more innovative and inclusive approaches to employment, including social and microenterprises, and strengthening the role of peer workers in the disability sector
- Ensure employment supports across services systems are tailored, connected and appropriate to the needs of people with disability, and providers are appropriately incentivised to help people who require the most support and tailored approaches to find and retain employment

Ensure investment in employment related support programs (across mainstream, foundational supports and the NDIS), research and initiatives are planned, coordinated and complementary across the Australian Government and state and territory governments.

2.7. The lack of available or affordable supports outside the NDIS for people with disability is leading to people missing out on the help they need

The limited availability of disability supports outside of the NDIS means people either miss out on needed support or join the NDIS to acquire it. Improving the availability of less intensive disability supports, including HACC type supports such as domestic and personal assistance and low-cost aids and equipment, will improve people's wellbeing and can contribute the sustainability of the NDIS.

2.7.1. There are large support gaps outside the NDIS for people requiring HACC related supports, disproportionality impacting specific groups, such as those with chronic health conditions

We have heard that many people with disability who are found to be ineligible for the NDIS are missing out on the support they need. This includes a significant number of people with chronic health conditions (CHCs), who serve as an example of who would benefit from greater provision of HACC related supports outside the NDIS.

CHCs can be described simply as 'long lasting conditions with persistent effects,' that impact on a person's quality of life.[128] This can include health conditions people develop over time, such as arthritis or osteoporosis, and may be influenced by diet and lifestyle factors, such as heart disease, type 2 diabetes, and kidney disease.[129] CHCs can lead to impairment and disability, meaning that people with CHCs may need support to live independently and fully participate in their communities.

> *"I have a Chronic Fatigue diagnosis. With this type of diagnosis, the NDIS (as well as Disability Pension) are very difficult to receive. ... I'm often unable to do basic day to day tasks or drive distances, and I'm only able to work about 1.5 hours a week." – Person with disability[130]*

> *"People with chronic illnesses need just as much support ... Causes stress, deterioration of current disability and conditions, increased feelings of hopelessness and isolation, lack of appropriate supports and interventions, hopelessness about one's future and prolonged suffering" – Person with disability[131]*

Under the Applied Principles and Tables of Support (APTOS) state and territory health systems are currently responsible for early intervention and treatment of chronic health conditions.[132] While chronic disease is recognised as a national health reform priority as part of the National Strategic Framework for Chronic Conditions (Chronic Conditions Framework), it does not address daily living supports where a chronic condition leads to disability.[133] As such, the relationship between the NDIS and health systems in supporting people with chronic health conditions remains ambiguous.[134]

People with CHCs may seek support through the NDIS, including for domestic and personal assistance, such as shopping, cooking and cleaning. The NDIA estimates there were around 41,500 people with CHCs as a primary disability in the NDIS as at the end of 2022, with an average

payments of around $62,000 per person and an overall cost of $2.46 billion per year or around 9 per cent of scheme costs.[135]

However, in many cases, people with disability associated with CHCs are not eligible for the NDIS. As at the end of 2022, around 108,000 people, have been found ineligible for the NDIS, around 56,000 of whom have CHCs.[136] Taking into account people who join the scheme after initially unsuccessful attempts, this still leaves around 50,000 people outside the scheme who did not manage to enter. There are several factors that contribute to people with CHCs being found ineligible for the NDIS, including that disability associated with a CHC is not considered a permanent impairment, or that it could be substantially alleviated through available treatments.

The importance of more adequate support outside the NDIS for people with CHCs is highlighted by NDIA data which shows that:

- An increasing proportion of adult scheme applicants have CHCs with 43 per cent of applicants aged 35 or older at the end of 2022 presented with a CHC primary condition
- Access met rates for adult applicants with CHCs have declined strongly since mid-2020 and are reaching very low levels (25 per cent per quarter as per end of 2022) relative to non-CHC applicants (73 per cent)
- The number of new entrants to the Scheme with a CHC has continued to decline, following lower access met rates, and now averages around 1,000 per quarter, meaning around 2,500 people with CHCs are found ineligible each quarter.[137]

This means that the number of people missing out on support is growing, and the pressure on the NDIS to meet these needs is growing. Action is needed to expand the availability of less intensive disability supports outside the NDIS to meet this need.

2.7.2. Expanded HACC type programs present an opportunity to improve the availability and quality of personal and domestic care for people outside the NDIS

HACC type programs for people under 65 deliver lower intensity disability supports such as personal and domestic assistance. State and territory programs are available for people with chronic-health related conditions, as well as other disabilities, including people with psychosocial disability. There is an opportunity to expand existing programs to meet the support needs of people outside the NDIS and to improve the sustainability of the NDIS.

HACC type programs offer well established mechanisms to deliver needed lower intensity supports and services with a high degree of certainty, effectiveness, and efficiency.[138] A number of state and territory governments have told us they are often the safety net that catches people who are not found eligible for the NDIS, or simply have no other program to turn to.[139]

When designing the NDIS in 2011, the PC identified HACC as a key plank of what they considered foundational (Tier 2) supports to be, envisaging that:

"All governments would continue to support a range of community and carer support services, including some existing or modified Home and Community Care services, for people with lower level or shorter-term disabilities." – Productivity Commission[140]

On average, state and territory programs provide support of approximately $3,000 to $4,000 per person. Based on data provided by state and territory governments, we estimate at least $293 million per annum is spent on HACC type programs for people under 65, and over 76,000 people with disability are supported Australia wide.[141] Under the National Health Reform Agreement, state and territory health systems are responsible for Home Care Packages for people aged under 65 years.[142]

Figure 9: State and territory home and community support programs for people under 65 statistics

	Program name/s	Activities	Eligibility	Yearly funding (2021/22)	Number of participants	Average cost per participant
NSW	Safe and Supported at Home[143]	Personal care Domestic assistance Home maintenance Respite services Referrals/linkages Activities vary slightly between jurisdiction (some jurisdictions offer medical transport, home modifications, advocacy, allied health, social support – some are time limited)	Generally under 65 (under 50 for First Nations people) Physical, sensory, psychosocial disabilities (most require someone not in NDIS or found ineligible) Functional limitations due to health conditions, physical, sensory, psychosocial disabilities. Client characteristics vary between jurisdiction	No data provided		
VIC	Home and Community Care Program for Younger People[144]			$207.5 million	60,000	$3,453
QLD	Queensland Community Support Scheme[145]			$30.9 million	9,000	$3,443
SA	Community Connections Care Partner services (being phased out as of 30 June 2023)[146]			$19.1 million	No data provided	
TAS	Home and Community Care[147]			$16.9 million	5,000	~$4,000
ACT	Community Assistance and Support Program, Flexible Family Support, Transitional Care Program (From 2023-24: Community Assistance and Temporary Supports)[148]			$9.8 million (all 3 combined in 2022-23)	2,600	$3,765

NT	Not provided			$9.0 million	No data provided
WA	No data provided – note, WA is transitioning away from HACC supports to support only through the NDIS.[149]				
Figures based on data provided by states and territories (each state and territory records data differently, and we did not receive data from NSW or WA, or from NT or SA for population)			**> $293 million**	**> 76,000**	**$3,000 - $4000**

However, HACC type programs are delivered inconsistently across the country. Some HACC type programs include the provision of aids and equipment and home modifications, while others do not. We have heard the NDIS and HACC type programs are poorly connected and it is difficult for people to navigate to the best supports available for them.

Most significantly, funding and HACC places are highly variable across different states and territories. People with disability have commented that there are insufficient HACC type supports outside the NDIS, including those people who lost access to HACC type supports as states and territories transitioned to the NDIS.[150]

> *"Basic requirements, such as gardening, cleaning, handy person assistance should be accessible outside of the NDIS. So should one off modifications or aids that need replacing that are permanent. To have to access NDIS, deal with unqualified planners, get a sum of money that may or may not be adequate, and be reviewed yearly for permanent disabilities…Is an insane waste of administration." – Person with disability[151]*

> *"People like myself have been left completely stranded without any avenue for help. My house cleaning and lawn mowing were cancelled when the NDIS started and have never been replaced. I have been rejected by the NDIS three times now." – Person with disability[152]*

> *"Gaining access to support can [be] an all-or-nothing situation- you're either on NDIS or you're not." – Person with disability[153]*

The Melbourne Disability Institute found that support gaps outside the NDIS were often filled through informal support from friends and family, and that many would benefit from some form of less intensive support outside the NDIS, like domestic and personal assistance.[154]

In the aged care system, the Commonwealth Home Support Program (CHSP) provides support for less complex support needs in a similar way to HACC programs.[155] In fact, in many jurisdictions CHSP is a direct continuation of HACC programs that split out into serving people above and below the age of 65.[156] This makes CHSP a very close analogue for HACC programs.

Of the 1.2 million people using the aged care system, 800,000 use the CHSP, while the remaining 400,000 rely on other programs designed for increasingly complex support needs.[157] That is a ratio of two CHSP places for every one place in the more intensive settings. This makes sense. We expect to see a great many more people in need of less intensive supports than those who need more intensive supports.

When we look at people aged below 65, the ratio of HACC to NDIS supports ranges from 1 HACC place for every 1.4 to 1.5 NDIS plans in Victoria and Tasmania, but in other states there might be only 1 HACC place for every 2 to 10 NDIS plans (Figure 10).

Figure 10: HACC and NDIS places, proportionate to state and territory population[158]
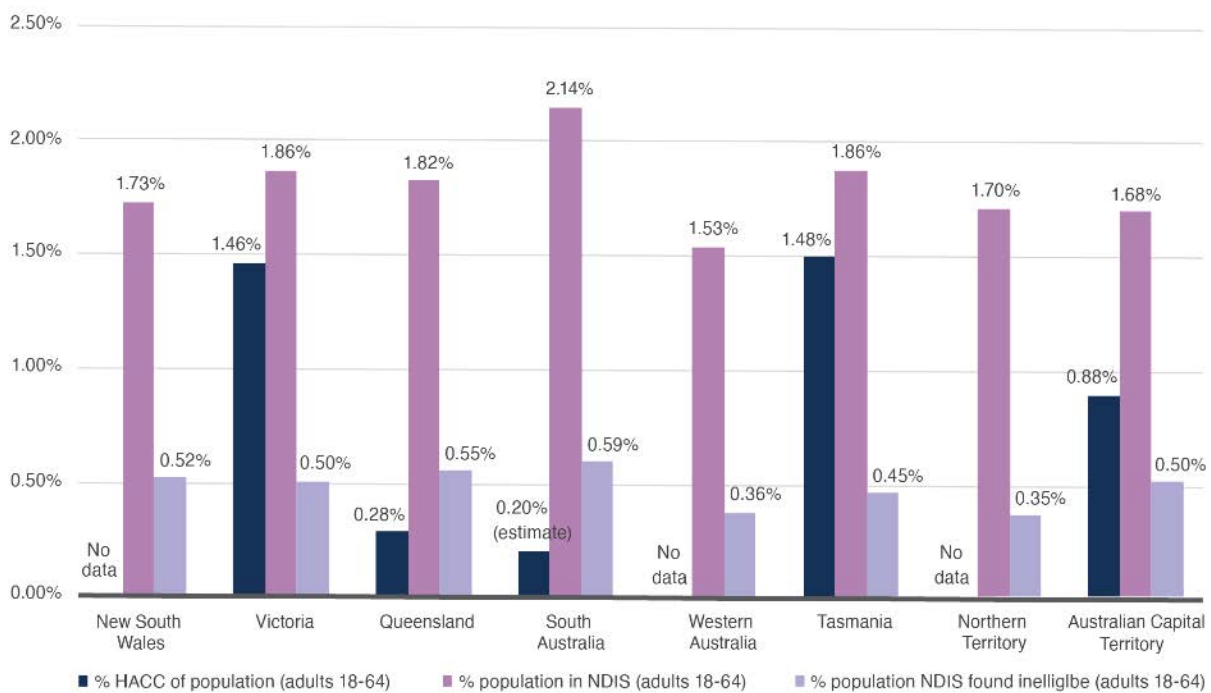
If we calculate the HACC share of the adult population aged under 65 in Tasmania and Victoria (1.5 per cent), which have the highest shares in the country (while the NT didn't provide data on how many people are using HACC, they likely also have a high proportion of HACC users based on funding data), we find that there would be around 235,000 places across Australia if this was matched in every state and territory. Using a jurisdiction such as the ACT with 0.9 per cent of the adult population, then this would work out to around 145,000 places across Australia.[159]

The number of adults under 65 who have self-identified a need for support by applying unsuccessfully for the NDIS, and who remain outside the NDIS, is close to 77,000 as of 31 December 2022.[160] It is reasonable to assume people in this group would likely comprise those most in need of HACC supports, and that they, and some people who accessed the NDIS, would not have sought support from the NDIS if adequate HACC type supports were available.

While the exact level of unmet need is uncertain, there is a clear need for more HACC type places than are currently available. The delivery of adequate foundational supports through HACC will

make the system fairer for those people with disability outside the NDIS who currently miss out on care and support.

It is also likely to reduce pressure on the NDIS. If people have support through HACC, attempts to seek this same support inside the NDIS should decline. In addition, it could reduce the risk of deterioration in conditions leading to higher levels of impairment. HACC supports should also help those receiving it, and their informal support networks, maintain a higher level of social and economic participation than would otherwise be possible. We estimate that if one person using HACC did not need to access the NDIS, this could fund around 10 HACC places.

We think there is a need to increase the number of HACC places offered in Australia to those aged under 65. We consider a benchmark for each state and territory of around 1.5 per cent of the 18 to 64 adult population, or around 235,000 places overall, is appropriate because of the evidence of unmet demand and the existing scope of HACC type supports in states and territories. Some states, such as Victoria and Tasmania, may comfortably meet this benchmark, others will need a significant uplift.

Due to the disparity between HACC offerings in each state and territory, this should be coupled with evaluation of the impact HACC places on the people using them and on the NDIS. This should then be used to determine a nationally consistent framework for HACC type supports, its relationship with the NDIS, whether coverage benchmarks should increase, and whether benchmarks for HACC quality and coverage are being met in each state and territory.

2.7.3. The provision of aids and equipment outside the NDIS is complex, inconsistent, and hard to navigate for people with disability

Assistive technology (AT) includes any aids and equipment that helps a person reduce the impacts of their disability.[161] It can include things like wheelchairs, hearing aids, ramps, and consumables. AT can improve people's social engagement, reduce reliance on other supports, and reduce risks of harm.[162]

AT is diverse but is often grouped into broad categories. This can include by complexity and by cost, where

- Low-risk AT includes off-the-shelf and low-cost daily living aids like continence pads or special can-openers.
- Under-advice AT includes products that need some advice and training, like walking frames or personal alarms.
- Prescribed AT includes more complex and/or costly products like powered wheelchairs and hoists.[163]

Studies have generally supported the benefits of AT tend to outweigh the costs, both for the individual accessing AT and in terms of the economic benefits for governments.[164]

Despite the recognised value of AT, access outside of the NDIS is widely considered to be under funded, fragmented, and complex.[165] The Assistive Technology for All Campaign, which comprises

many disabled people's organisations, has identified that access to AT for people outside the NDIS is inadequate.[166]

There are approximately 108 different schemes, in addition to the NDIS, where AT can be provided, each with different eligibility criteria.[167] These schemes are mainly funded by states and territory governments, split across multiple portfolios such as injury insurance, health and education.[168] We have heard this creates both confusion and inconsistency for people seeking to use these programs.[169] In comparison to the NDIS, these schemes may include long wait-times, co-payments, and poor ongoing or 'wraparound' support to ensure people get the most out of the AT they do get.[170]

> *"There is a distinct lack of equity and consistency across the 108 assistive technology schemes operating outside the NDIS. People with similar needs receive different amounts of support depending on their age, geographic location and when and where their disability was acquired." – Research paper[171]*

The gap between AT available inside and outside the NDIS is not balanced or fair, and puts financial stress on the NDIS. It leads to people with disability applying for and staying in the NDIS for fear of a lack of support outside of it, and people who cannot access the NDIS are missing out on vital supports and services, increasing future needs.

The interface between the NDIS and AT programs should be simplified and opportunities for efficiencies should be explored. The gap between the types of AT available inside and outside the NDIS should be reduced. To improve the experience and wellbeing of people outside the NDIS there should be:

- Better provision of AT outside the NDIS – the current level of funding for and availability of lower complexity, lower cost AT could be expanded
- Better coordination and information on what is available and where to get it – the complexity of the current system can and should be made more manageable, either by consolidating programs or by improving navigation to find the right one
- Better use of government buying power to drive efficiencies in supply through provider panels (see Chapter 4 and Recommendation 11)
- Better wrap-around support and training for people to use the AT they have access to – as currently someone may manage to receive AT but may not be adequately supported to use it to its greatest benefit.

This could be achieved through:

- The proposed Navigator function (see Recommendation 4) supporting people with disability more easily find and access existing AT programs
- In the expanded HACC programs, considering whether the expansion of HACC should include the provision of AT in those jurisdictions that don't have it already
- For better integration of the disability and aged care systems, the Australian Government Department of Health and Aged Care should work with DSS to consider where current work

looking at how to better provide AT to older people can be expanded to be inclusive of all people with disability, including those using AT provided within the Health and Veteran's Affairs portfolios.

The Care and Economy Taskforce has also investigated this issue and is considering actions that are aligned to those explored here. We suggest this is a holistic and interlinked body of work that, if done right, can improve social and economic outcomes for people with disability, and reduce the impact of people's disability over time.

2.7.4. Action & Implementation Details

Action 1.9: National Cabinet should agree to jointly invest in state and territory home and community care support programs to provide additional support to people with disability outside the NDIS

This would support people with disability across Australia, including people with chronic health conditions, to access domestic and personal assistance in their home and community. To ensure service quality and equitable coverage, this investment should be supported by an agreed nationally consistent framework and a benchmark for minimum support standards and coverage.

Implementation detail:

Australian Governments, through their Foundational Supports Statement of Intent, should agree to jointly fund and then work with states and territory governments for them to:

- Expand the delivery of community-based home support programs (including home and community care (HACC) and similar programs) for adults with disability under the age of 65 with lower intensity and episodic needs
- Aim to achieve a benchmark of 1.5 per cent of the adult population aged 18 to 64 in each jurisdiction, or around 235,000 home and community care style places nationally
- Simplify and improve the pathways between the NDIS and HACC programs.

The Australian Government, working with states and territory governments should:

- Evaluate HACC type expansion in each jurisdiction within 24 months of rollout, with regard to the impact on those using it and the impact on NDIS costs
- Determine and recommend adequate coverage levels for each state and territory
- Develop and implement a nationally consistent framework for the delivery of effective, efficient and localised models of HACC programs administered by states and territories with a minimum standard of support for each person
- Develop and provide public national reporting of state and territory programs against quality and coverage indicators.

Based on evaluation, if unmet need remains, states and territory governments should develop an implementation pathway to expand the programs to a level that meets unmet need in each state and territory and improves the sustainability of the NDIS.

Action 1.10: The Department of Social Services, with states and territories, should develop a nationally consistent approach for the delivery of aids and equipment outside the NDIS

This should be focused on improved planning and coordination of aids and equipment between the NDIS, health and aged care sectors and across jurisdictions. It should also identify an efficient and effective mechanism to fund aids and equipment outside the NDIS. This could include the provision of some aids and equipment (such as hearing assessments and aids) as a targeted foundational support.

Implementation detail:

This approach should:

- Simplify and improve how to find and access independent, quality, and consistent information and advice on aids equipment across jurisdictions
- Design and deliver more efficient and effective funding and service delivery mechanisms for the provision of aids and equipment outside the NDIS
- Simplify the interface between the NDIS and aids and equipment programs delivered outside the NDIS
- Consider jointly commissioning some aids and equipment (such as hearing assessments and aids) to meet the targeted foundational support needs of people outside the NDIS and support needs of participants through a NDIS individualised budgets
- Review and evaluate the effectiveness, appropriateness, and how investment is planned and coordination in current Australian Government and state and territory government aids and equipment programs, including home and community care programs and across the health, aged care and veterans affairs portfolios.

2.8.   Psychosocial supports outside the NDIS are inadequate and fragmented

2.8.1.   Many people with severe and persistent mental ill-health cannot access psychosocial supports through the NDIS or non-NDIS services

Psychosocial supports are non-clinical services that assist people with psychosocial disability to build personal capability and stability in areas such as relationships, day-to-day living skills, housing, education and employment. Non-NDIS psychosocial supports are a joint Australian

Government and state and territory government responsibility.[172] Current services are primarily administered by Australian Government, state and territory government mental health systems, and delivered by non-government organisations (NGOs). Services include:

- State and territory government programs, which generally focus on people with severe mental ill-health who are receiving clinical treatment but are ineligible for the NDIS. In 2020-21, state and territory governments provided $462 million in grants to NGOs for psychosocial support activities (note this does not include all types of psychosocial supports, or more recent investments in jurisdictions such as Victoria).[173]
- The Australian Government Psychosocial Support Program, administered through Primary Health Networks provides short-term, low intensity supports for people who are not receiving similar supports through the NDIS or state and territory psychosocial support programs. This program is funded at $130 million per annum until June 2025.[174]

Notwithstanding existing support programs, many people with psychosocial disability are missing out. In 2020, the Productivity Commission, in its Mental Health Inquiry, estimated that of the 290,000 people with severe and persistent mental illness around 75,000 received supports from Australian Government, state or territory government programs outside the NDIS and around 64,000 were expected to be NDIS participants by full roll out (including an estimated 3,000 people moving across from non-NDIS programs). This left approximately 154,000 people unable to access psychosocial support services.[175]

> *"Psychosocial supports are very challenging to get assistance with. This should not be such a challenge for those with these needs to access the support they need." – Carer[176]*

> *"[T]here were no community based mental health supports that would help [my brother] without an NDIS plan. State based mental health pushed him away because he had chronic psychosocial disability and was therefore outside of their remit of acute mental illness but he wasn't deemed functionally incapacitated enough to be an NDIS participant." – Participant[177]*

As at June 2023, the NDIS ineligibility rate for primary psychosocial disability is 30 per cent compared to 15 per cent for the overall scheme.[178] While likely partly due to a requirement to test eligibility under non-NDIS programs, the high rate of people testing access for the NDIS and being found ineligible highlights there are many non-participants who need assistance.[179]

2.8.2. There are long-standing gaps in, and fragmentation of, non-NDIS psychosocial support programs

The gap in supports is due to several factors.

- There were gaps in psychosocial support prior to the introduction of the NDIS which have not been addressed. While the total number of people receiving psychosocial supports has

increased (from approximately 95,000 in 2016–17 to 110,000 in 2019–20),[180] there remains significant unmet need.

- During the transition to the NDIS, many programs, including the Australian Government Partners in Recovery and Personal Helpers and Mentors programs, were discontinued. To support people ineligible for the NDIS, the Australian Government established the Continuity of Support and National Psychosocial Support Measure programs, which were consolidated into the Commonwealth Psychosocial Support Program in 2021. However, there was significant uncertainty during this transition about which services would continue, with some people falling through the cracks and losing support.[181]
- Current non-NDIS psychosocial support arrangements are relatively ineffective, comprising several small-scale programs, with little transparency and consistency, and short-term funding contracts.[182]
- The respective eligibility requirements and coverage of the NDIS and various non-NDIS psychosocial support programs are unclear, and there is little policy and operational engagement between the NDIS and mental health system.
- The complexity of the NDIS application process and lack of outreach means that some people who would likely be eligible are not participants.[183]

2.8.3. Health Ministers, under the National Mental Health and Suicide Prevention Agreement, are considering future arrangements for non-NDIS psychosocial supports

In 2022, under the National Mental Health and Suicide Prevention (NMHSP) Agreement, jurisdictions agreed to work together to develop future psychosocial support arrangements for people who are not supported through the NDIS.[184] The Australian Government, states and territories are conducting a gap analysis of existing programs, at a regional level, which is due for completion by March 2024. Governments have committed to develop a future approach, to be attached as a schedule to the NMHSP Agreement.

Under the NMHSP Agreement, the broader landscape in mental health services is also changing. This includes expanding community mental health and addressing the largely artificial siloing of psychosocial and clinical mental health services – a weakness of the current service ecosystem.[185] In Victoria, in response to the Mental Health Royal Commission, community mental health services will deliver integrated treatment, psychosocial, education, peer support, and coordination services. This includes area mental health and wellbeing services, delivered in partnership between public health services and NGOs, for people with severe mental ill-health.[186]

2.8.4. Reform is vital to position the NDIS as the upper end of a continuum of psychosocial supports which are accessible and assist people to build independence

Addressing gaps in current arrangements through the NMHSP Agreement is vital. Expanding existing programs would assist people to improve their quality of life and pursue employment opportunities.[187] It would also assist with improving NDIS sustainability. Early access to

psychosocial supports (combined with mental health treatment) may reduce the likelihood of requiring the NDIS in the future, as well as relieving pressure on hospitals and other services.[188]

> *"If people with psychosocial disability who are currently ineligible for the NDIS do not have access to appropriate psychosocial support outside the NDIS, their disability may deteriorate to a level where NDIS supports are required. … [T]he lack of a well-functioning and effective mainstream system for providing psychosocial supports for people not eligible for the NDIS is a key risk in containing the long-term costs of the NDIS." – Mental Illness Fellowship of Australia, Mental Health Australia and Community Mental Health Australia [189]*

Non-NDIS supports can also be significantly lower-cost than NDIS coverage. The Commonwealth Psychosocial Support Program, for example, has an average annual cost of approximately $6,000 per person.[190] By comparison, as at June 2023 the average NDIS annualised plan funding of participants with primary psychosocial disability who do not have Supported Independent Living (SIL) supports was $77,200.[191] It should be noted that, in addition to psychosocial supports, some people also need access to other disability services.

Through the existing NMHSP Agreement process, governments should expand programs within the mental health system to increase access to non-NDIS psychosocial supports. This should be part of a systemic approach to psychosocial disability - one which develops a continuum of NDIS and non-NDIS supports, complemented by accessible treatment through increased collaboration between disability and health portfolios. Reforms should address the inefficiency of current fragmented programs, reduce siloing of mental health and psychosocial services, and clarify coverage and accountability of NDIS and non-NDIS psychosocial supports.

2.8.5. Expanding and consolidating non-NDIS psychosocial supports will require a significant investment commensurate with unmet need

The design of these reforms should draw on the Productivity Commission's recommendations, as well as new findings from the service gap analysis and broader directions in mental health reform — including the expansion of community mental health services. Details of a future approach should be negotiated under the NMHSP Agreement. Nonetheless, expanding non-NDIS psychosocial supports requires significant investment.

In 2020, the Productivity Commission estimated that expanding psychosocial support to cover the 154,000 non-participants missing out would require an additional $610 million per annum (over $650 million, adjusted for inflation).[192] A recent report commissioned by the Office of the Chief Psychiatrist in South Australia estimated the funding shortfall in South Australia alone could be as high as $125 million per annum.[193]

2.8.6. Action & Implementation Details

Action 1.11: <u>National Cabinet</u> should agree to jointly invest in psychosocial supports outside the NDIS to assist people with severe and persistent mental ill-health currently unable to access supports.

Consistent with the recommendations of the Productivity Commission's 2020 Mental Health Inquiry, this would expand and consolidate the Australian Government's Psychosocial Support Program and existing state and territory psychosocial support programs to help address the significant unmet need. The expansion would be managed and delivered under the National Mental Health and Suicide Prevention Agreement and updated based on findings from a service gap analysis currently being led by Health Ministers (due for completion by March 2024).

Implementation detail:

Australian Governments, through their Foundational Supports Statement of Intent, should commit to build up over time future funding arrangements for psychosocial supports outside the NDIS to:

*   Address significant unmet need in current supports, which the Productivity Commission estimated in 2020 as affecting 154,000 people and will be further defined through the current gap analysis process examining services at a regional level.
*   Develop a deep and effective collaboration between health and disability portfolios, noting the importance of non-NDIS psychosocial supports for the effectiveness and sustainability of the NDIS.

2.9.   There are few supports for children and their families outside the NDIS

We have seen the approach to supporting children with disability or developmental concerns and their families is not working. A lack of a coordinated approach across governments has meant that there are significant gaps in the accessibility and availability of supports.

This is seeing children miss out during the unique period of rapid brain development that plays a critical role in shaping a person's life trajectory. This is an important window to improve long-term outcomes.

This is not just an issue for the NDIS. Around one in five children in Australia have disability or developmental concerns by the time they reach school.[194] This an issue that requires a coordinated response across all service systems and governments.

"There is no 'joined up system'. All levels of government 'know' our son: he was born in a [state] hospital, he has been receiving health care and immunisations since birth, he attends a council-run preschool, he was diagnosed with autism in a [state] hospital, and now we are enrolling him with [state] schools - and yet EVERY SINGLE TIME we deal with one of these services, we start from scratch explaining his history, his needs, his diagnosis."- Carer[195]

We have heard that many families have either had to go without support or seek access to the NDIS. It's not surprising that families have sought access to the NDIS when there is so little available outside of it and many mainstream services push children and families towards it.

"The barriers that exist between NDIS plans, Tier 2, health, education and other systems all create complexity and challenges in accessing services and create artificial barriers (e.g. between funding bodies) that impact access to necessary care and supports." - Occupational Therapy Australia[196]

In the future, there should a wider range of supports outside the NDIS for children and families that are more responsive to different types and levels of need. This will require a series of reforms across service systems and the NDIS. It requires all governments to work together.

2.9.1.   Supports outside the NDIS are inadequate to meet the needs of children and families

There are a significant number of children with developmental concerns or disability who require different or a higher level of support than is currently provided by mainstream services. But they may not require the level of specialist support provided as part of a NDIS individualised budget.

These children and their families typically require early supports and/or dedicated family capacity building supports.

Early supports for children with developmental concerns or disability

Currently, some children with developmental concerns and disability are referred to Early Supports provided by NDIA Early Childhood Partners. These are intended to respond to need and build capacity in both children and families.

Early Supports are a type of Early Connections that an Early Childhood Partner may provide. They may also provide connections to mainstream and community supports, provide access to information or peers support, or support an access request for the NDIS.

An introduction to the current approach to early supports is provided below.

Introduction to Early Supports in the NDIS[197]

Early Childhood Partners may recommend Early Supports for children who are younger than six and have developmental concerns.

Early Supports are intended to build capacity in both families and children across natural settings. They promote everyday learning in the home and other environments.

Early Supports are intended to follow the principles of best practice as outlined in the National Guidelines on Best Practice in Early Childhood Intervention.[198]

Prior to the implementation of the NDIA Early Childhood Early Intervention Reset Project (NDIA Reset Project), Early Supports were known as Short Term Early Intervention (STEI).

Who:

Early Supports are delivered by Early Childhood Partners who work with families to understand their child's strengths, needs and identify what supports are needed.

Early Childhood Partners are responsible for determining whether to offer Early Supports to a child. In making this decision, they look at whether:

- Their observations of the child and parent report show concerns about the child's development.

- The assessment and screening tools show the child's development is outside the typical range for their age.

- There are developmental concerns that don't fully meet developmental delay.

- There is any evidence from relevant professionals to show there's a significant impact on the child's function or the impact isn't yet known.

- The support required is the responsibility of mainstream and community services.

What:

Early Childhood Partners work with families to identify what is needed for the child and family. This is put into an Early Support Plan which documents goals, likely support needs including possible resources or strategies, circumstances and next steps.

Early Supports can be provided in individual or group settings, and may include:

- Parent workshops on child development topics such as behaviour, feeding or toileting.

- Building the skills and capacity of mainstream services, such as early childhood education and care services, to support the child's needs.

- Strategies to help the child build their skills and participate in everyday routines – such as visual supports for communication, or changes to the child's environment to support their participation.

- Support to build the family's confidence and knowledge to use the strategies and skills in everyday routines.

- Working with families and mainstream services to prepare for upcoming transitions, such as starting school or preschool.

When:

The Early Childhood Partner will determine how long Early Supports are needed for, but it is usually 3 to 6 months, or up to a maximum of 12 months.

We have heard that the maximum amount of support is 17 hours per annum and the actual availability of the support depends on the resourcing constraints of the Early Childhood Partner.[199]

If the child becomes a participant the Early Supports will stop and the Early Childhood Partner will work with the family to develop the child's NDIS plan.

We have heard about a number of challenges with the existing Early Support program delivered by Early Childhood Partners. Specifically, supports are not widely available and there is lack of integration between Early Childhood Partners and the broader child development system.

> *"We really have not had the opportunity to be doing early supports, which is that we've got trained skilled staff who've got those early childhood qualifications, and they haven't had the opportunities to actually focus on being there on the ground really early on." – Anonymous[200]*

> *"It's like, 'Oh gosh, we're stepping out of this really valuable navigation role for families and delving into something that I don't think we belong there.' I don't see it as our space, I see it as mainstream community's responsibility to provide that to families, so…" – Anonymous[201]*

Early Childhood Partners largely focus on metropolitan and regional centres, which means that supports are not always widely available and in some communities there are no early supports at all. Where they are available, uptake of Early Supports remains relatively low. This suggests that families don't currently view it as an appropriate and effective way to support their child. As of 30 June 2023, only around 18,000 children were accessing Early Connections.[202]

Early Supports is a subset of Early Connections. By comparison, there were almost 100,000 participants under the age of six in the NDIS at the same point in time - more than five times as many accessing Early Connections.[203] The NDIA Reset Project similarly found 'that the perception of STEI and Initial Supports needs to be improved among families and mainstream services, and that these early support initiatives are not a 'gateway' to the scheme and do not represent an inferior support'.

Part of this challenge is the limited and capped level of support provided. Critically, the 17 hours of support appears to be the maximum and the actual availability of the support depends on the resourcing constraints of the Early Childhood Partner.[204]

This is significantly less support than a child would receive in the NDIS even on the lowest end of plan values. There is a sizable difference between the "average amount of money spent on the 10 per cent of young children receiving early supports ($2,000 per year), compared to the 90 per cent with an individual support budget ($17,900 per year)".[205] While these figures predate efforts by the NDIA to increase Early Childhood Partners capacity to deliver Early Supports, it highlights the large disparity in the level of support for those outside and those inside the NDIS.

> *"According to the recent tender, children with disability or developmental delay will be eligible for "early supports". They will receive a little more support - up to 17.2 hours per child, which is available over a maximum period of 12 months, but they will be limited to accessing these early supports only once and the NDIA estimates that only 4,200 children nationally will be eligible. Early supports are payable to the EC partner on a "part-variable payment" basis, meaning that actual provision of these services will be limited by the resourcing of the EC partner" – Healthy Trajectories Child and Youth Disability Research Hub[206]*

Unpublished data supplied by the NDIA indicates that average 'effort hours' a child receives under Early Supports is substantially lower than Early Connections.[207] This is also significantly less than is available under a lower value plan. See Figure 11 for the hours currently being delivered. While Early Connections may involve a more intensive effort of gathering information to inform an access request under developmental delay, delivery of Early Supports also involves the development of an Early Supports Plan.

By comparison, a participant with an annual plan of $18,000 could potentially access 93 hours of therapy per year, or roughly 7.7 hours of therapy per month (assuming $193 per hour). This is more than three times as much as the average amount of Early Supports suggested below. The participant also has the benefit of it being an annual amount and access to a choice of therapists.

Figure 11: Effort hours across Early Connections and Early Supports for a child before they exit[208]

Support type	Average monthly effort hours
Early Connections and Early Supports	4 hours and 38 minutes
Early Connections only	4 hours and 5 minutes
Early Supports only	2 hours and 31 minutes

An added complication is that the delivery of Early Supports has been effectively situated inside the NDIS by using Early Childhood Partners to deliver the support. Early Childhood Partners are a key access point to the NDIS for young children. Early childhood professionals and researchers are concerned that this has meant that Early Childhood Partners have become part of the disability

service system and are not closely linked to the broader child development ecosystem of early childhood education and care, education, health and recreational services in communities.[209]

We also heard about the significant gap in services for children in remote and very remote locations. This disproportionately impacts Aboriginal and Torres Strait Islander children. We heard about the successful Remote Early Childhood Service (RECS) model delivered in the Kimberley region of Western Australia. The same model is not available more broadly in Western Australia. Previous locations that were delivering the RECS model have had to cease, due to contracts ending.[210] There are also severe allied health shortages in Western Australia which is resulting in long wait lists.[211]

This is currently being examined in a Western Australian parliamentary inquiry into child development services.

> *"There are currently 17,000 children in WA waiting to access services such as speech pathology, physiotherapy and occupational therapy, with wait lists for children to see audiologists, clinical psychologists, OTs and speech pathologists just as high"* – Aboriginal Health Council of Western Australia[212]

The NDIA Reset Project identified the need to implement tailored early childhood services and methods for Aboriginal and Torres Strait Islander families and children (see Chapter 2). In their submission, the Aboriginal Health Council of Western Australia noted that they haven't seen the benefits of this intended increase in support.[213]

Support for families of children with developmental concerns or disability

Most people have no experience of developmental concerns or disability until it occurs within their own families. It can be a highly overwhelming time. Families need to be empowered with information, education and peer support from other families so they can build skills and confidence to support their child.

Families of children with developmental concerns or disability experience additional stress and demands on their time. Additional support is critical to mitigating the isolation, exhaustion and stress that families and caregivers experience.

> *"For parents and carers faced with the prospect of a lifelong disability for their child, it can be very overwhelming as they are dealing with their own grief and shock. They need to be steered to advocates who can help them navigate where best their child can have their needs met, and which professionals need to be involved."* – Carer[214]

There are currently patchy approaches to supporting families early in their child's journey, including through counselling. There are some capacity building organisations providing valuable support, however this is not widely available. We have heard that families currently have limited access to capacity building and peer support despite the evidence of its impact and cost effectiveness. There is also limited access to neurodiversity affirming organisations that promote contemporary models of disability and positive visioning and inclusion.

Funding for family capacity building services is typically provided through grants as part of the ILC Program. However, the ILC Program has struggled to respond to the need of families of young children with developmental concerns and disability.

There are a range of funded initiatives that aim to support families or parents and build their capacity through information, online communities, peer support and leadership. This means there are high-quality existing initiatives, but there is no approach to ensuring these are consistently available for families across Australia.

A grant-based approach encourages a range of disparate projects that can overlap and leave gaps at the same time. It is reliant on there being organisations to identify the need, develop a solution and be successful through the grant round. This leaves much to chance when there is clear evidence of significant benefits from building the skills and confidence of families to support their child.

> **Box 1: An introduction to family capacity building**
>
> Family capacity building essentially means supports for families of children with developmental concerns or disabilities. It can take a range of forms and include:
>
> - Information
> - Education
> - Connections to other families, including siblings
> - Family leadership and empowerment

The National Early Childhood Program for Children with Disability and Developmental Concerns (NECP) has attempted to fill some of these gaps for children under nine and their families.[215] The NECP provides a range of information (Raising Children Network), workshops for parents (ENVISAGE-Families) and supported playgroups for children (Playconnect+). However, funding is limited to $17.9 million over four years.[216] This compares to $1.1 billion in committed NDIS supports for children aged younger than seven for the 6 months to 30 June 2023.[217] There is clearly a significant disparity between what is available for those families inside versus outside the NDIS.

Research commissioned by DSS also found current peer support for families to be fragmented and disconnected from other service systems.[218] It noted there were significant gaps around systems navigation support and support for families of children who may not have a diagnosis, are not part of the NDIS or who are waiting to access supports.

Research indicates that families need capacity, confidence and knowledge to make informed decisions about their children.[219] Yet we have heard that families are 'cobbling together information about the best way forward'.[220] We have also heard the NDIS has inadvertently 'over-developed the specialised support laneway' to the detriment of community inclusion and parent-peer led approaches.[221] Families are having to fill in information gaps themselves and pick up the additional workload of navigating different supports and programs for their children.

"Over the 7 years, the most information I got was in the waiting room from other parents or some random conversation with the physiotherapist. There's no one place where one can go for information, you don't know what to google for? Most of us have no experience with special needs, so looking after your kids is hard enough let alone working everything else out." – Carer [222]

"I reflect on the four years that I lost. Four years of not seeing qualities that my daughter always had that were invisible to me, yet in plain sight..." – Plumtree Children's Services [223]

2.9.2. A continuum of support for children that better caters to different levels and types of need

Far more support should be available where children live, learn and play and reduce the pressure on families having to access the NDIS for support. Implementing a holistic and joined up continuum of supports for children with disability and developmental concerns should be an urgent priority for all governments.

Children with developmental concerns and disability should be matched with supports that best meet their needs. This requires improved accessibility and availability of mainstream and foundational supports. This would create a continuum of supports, matched to the needs of children and their families and relieve pressure on families to have to access the NDIS to be supported. An illustration of this continuum is provided in Figure 12 below.

Children with higher support needs should be able to access the NDIS through a more consistent and robust access process. Children who are eligible for the NDIS should receive a budget based on support needs, determined through child-specific assessments.

All early intervention supports for children, including those provided through the NDIS and foundational supports, should be evidence informed and based on evidence and principles of what works. Providers who deliver capacity building supports in the early childhood approach should be required to be registered to increase the uptake of best practice services. This should be complemented by a consistent approach to ongoing monitoring and evaluation of the effectiveness of early intervention for children.

Government is approaching a critical point for transformative change for children and families. There will soon be findings and recommendations available from the Early Years Strategy, National Autism Strategy, National School Reform Agreement, and Productivity Commission inquiry into the early childhood education and care sector, along with this Review.[224] These provide an opportunity for governments to strengthen the support available to children and families through mainstream and foundational service systems.

The proposed actions to improve mainstream supports as part of the continuum are set out in the Section 2.10 and the actions to improve the NDIS are set out in Chapter 2.

Figure 12: Overview of the future continuum of support for children and families
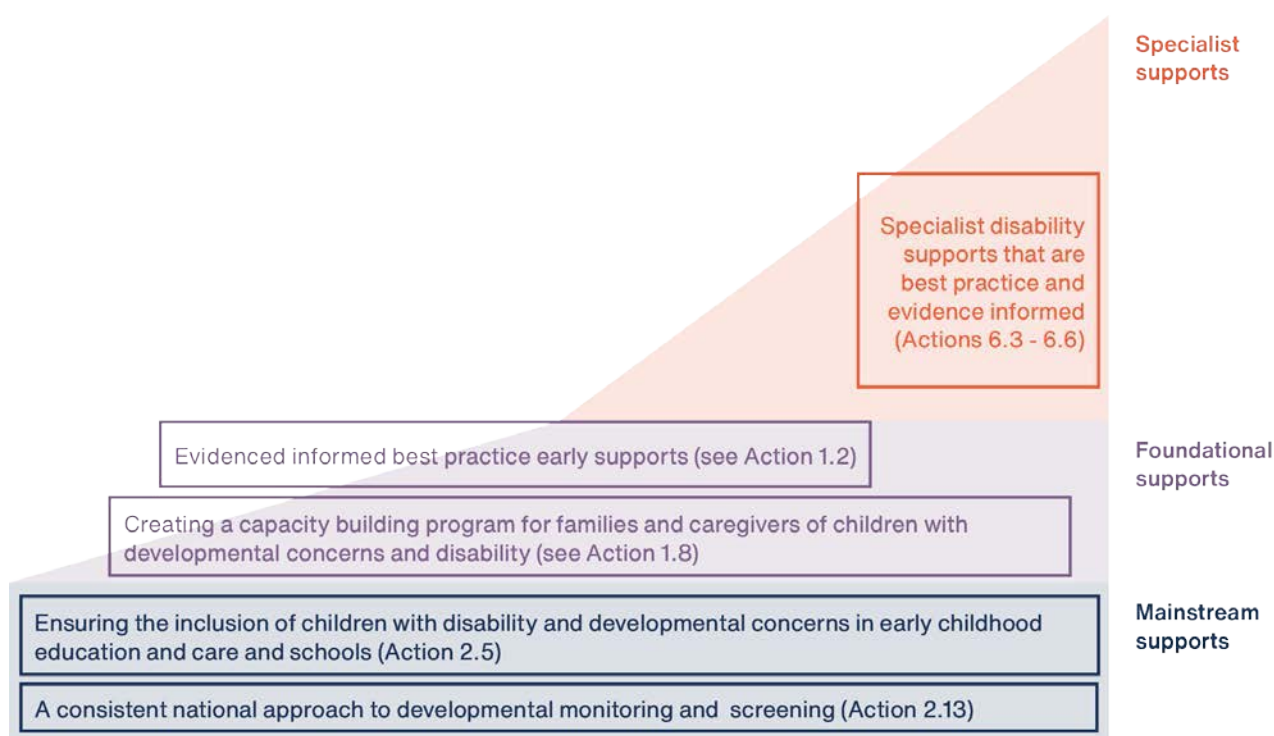
This should be achieved through the following actions that combine to create a continuum of supports that better caters to different levels and types of need:

1. **Mainstream systems**: A more consistent approach to identifying need and inclusively supporting children with developmental concerns and disability. Described in further detail in the Section 3.

2. **Foundational system**: Far more supports available outside the NDIS for children and families who have different or higher needs than mainstream supports can reasonably respond to. This is the focus of Section 2 and is covered in detail in Section 2.9.3.

3. **Specialist disability system**: A best practice approach in the NDIS to support children with developmental delay and disability and their families. This is described in further detail in the Chapter 2.

2.9.3. More widely available and effective supports for children are critical for delivering better outcomes

There should be far more foundational supports outside the NDIS. Support for child development when concerns emerge has the best chance of shifting developmental trajectories.

This investment is cost-effective in the long-term. Early intervention will result in lower need for specialised supports from the NDIS and for states and territories, investment in early intervention will save costs in preschool, school, vocational education and training, justice, and housing.

Foundational supports for children with developmental concerns or disability should include two offerings:

- Targeted foundational early supports for children and families with higher or more ongoing need.
- General foundational capacity building supports for families of children with developmental concerns, delay or low support needs for their disability. These should align with the broader approach to the proposed capacity building reforms (see Action 1.3).

There is a close interaction between both types of foundational supports. Both are based on the idea that well supported families lead to well supported children.

The early supports offering should be consistent with best practice principles. Best practice principles guide how early childhood practitioners work with families of children with developmental delay and disability. At its core, this means taking a family centred and inclusive approach.[225] Family centred means that planning, supports and outcomes consider the holistic needs of the family, not just the child with developmental concern or disability.

The capacity building supports for families should also be consistent with the best practice principles as it is specifically focused on enhancing the skills and confidence of the family and caregivers. It explicitly recognises the importance of supporting the family, including other caregivers and siblings. This should be part of a broader shift by government to meeting the holistic needs of the family, rather than continuing to direct funding towards the child in isolation from the family.

The distinction between the two offerings is early supports should target children with developmental concerns or disability and families who have higher or more ongoing needs. Whereas, family capacity building is envisaged to support all families, whether they only require a single workshop, to join a local peer support group, or need a combination of ongoing supports. A family with higher levels of need should be able to access offerings from both early supports and family capacity building. A NDIS participant would not be able to access early supports.

Funding for both early supports and family capacity building should be a fixed amount based on population and expected demand. It is not envisaged that foundational supports become demand driven and open-ended in the same way as the NDIS.

The two foundational offerings are described in further detail below.

Targeted early supports for children with developmental concerns or disability

In the future, more early supports should be available to help children build their skills and participate in everyday activities. They should also build the confidence and knowledge of families to support their child in everyday routines. This should be delivered through expanding the investments in early supports for children with emerging developmental concerns and disability and their families (see Action 1.12).

A reset is required in how early supports are being delivered. Currently the availability of support is constrained by the footprint and capacity of Early Childhood Partners who have been diverted from their intended role to carry out access and planning activities. It is also a capped level of support limited by the resourcing of the Early Childhood Partner and the low funding level. This has, understandably, resulted in families viewing it as an inferior offering compared to accessing the NDIS.

The future model of early supports should be far more flexible, accessible and responsive to need. It should include:

1. A national model of early support that is consistently available across Australia. This should include a national framework that sets out the minimum service requirements and allows for localised service models that are tailored to individual community needs and achieve the target outcomes. Organisations that are approved to provide Lead Practitioner supports in the NDIS are well placed to deliver these supports.

2. Discrete and place-based models of early support that are either trials of early intervention approaches that have been proven to work for particular conditions, cultures or demographics, or are unique place-based approaches. The intent is trials are evaluated and (subject to positive results) then scaled into the national model. The intent of the place-based approaches is to recognise that there may be specific locations where a national model isn't going to be effective and/or there are unique opportunities available to work with other mainstream services or community controlled organisations in a particular location.

Both approaches must be consistent with the best practice principles and be informed by contemporary evidence of what is effective. There needs to be an approach of continuous improvement, where there is an established process for trialling and evaluating a range of early support models.

In due course, and subject to the results from the trials committed to in the 2023-24 Australian Government Budget, the discrete models could include a scaling up of the Inklings program, which is designed to provide early, early supports for children showing signs that they may be neuro-diverse and their families.[226]

The delivery of these early supports should be closely linked to and integrated with mainstream services, particularly education and early childhood services.

National model of early supports

A national model of early supports should include support to help children who are not eligible for the NDIS to build their skills and participate in everyday activities. It should provide families with information about child development, building their confidence and knowledge to support their child in everyday routines. Supporting children through normal daily routines is designed to maximise support at all times, not just when the child attends a therapy session in a clinical setting.

It is designed to show families how they can be the most effective teacher of their child as they go about their day to day activities and not add to their workloads.

Organisations that are approved to provide Lead Practitioner supports in the NDIS are well placed to deliver these supports. This is because Lead Practitioners are required to have expertise in child development to be able to support families in an evidence informed, principles based way. They should be a qualified allied health practitioner, developmental educator or early childhood educator who is trained in an approach based on best practice principles.

In practice, this may mean the Lead Practitioner is responsible for leading small group sessions or working directly with the child and family. This will ensure a transdisciplinary approach, where the Lead Practitioner would play the primary role in coordinating and then delivering most (if not all) of the support.

Because early supports are for children outside of the NDIS, the coordination role of the Lead Practitioner is expected to be smaller compared to children inside the NDIS (as there will not be NDIS providers to coordinate). This would primarily involve coordinating other key stakeholders in the child's life, such as working with early education or schools to build their skills and capacity to support a particular child in these natural settings, or to prepare for upcoming transitions.

Importantly, a key role of a Lead Practitioner is to ensure a best-practice approach is used across all early intervention supports. This means they will be highly trained and experienced in the delivery of best practice supports. This provides an opportunity to ensure there is a consistent focus on the best practice principles across both foundational supports and the NDIS through the Lead Practitioner.

The design of the national model of early supports should consider whether additional capabilities are required to supplement the Lead Practitioner, or if Lead Practitioner organisations should be required to have a minimum breadth of capabilities to deliver early supports. This could include requiring a transdisciplinary team of professionals who provide supervision and support to the Lead Practitioner to enable them to deliver intervention strategies from outside their discipline.

The future early supports model needs to be designed carefully with families to ensure the process is family and child centred and supports the best practice principles. It should be informed by other experts in child development, service delivery and representative organisations. The design of the model has key dependencies with both achieving consensus on best practice for early childhood intervention and the design of the Lead Practitioner model (see Chapter 2 and Recommendation 6).

An overview of the potential future model is provided below in Box 2.

> **Box 2: A potential future national early supports model**
>
> NDIA or Navigators may recommend early supports for children who are younger than 9 and have developmental concerns. Early supports are expected to be aimed at very young

children. The children may have tested access to the NDIS and have completed a Needs Assessment that provides significant detail on the needs of the child and family.

These children may have been referred to a Navigator by maternal child health or an early childhood professional due to a developmental concern.

Early supports are based on the principles of best practice and are rights based. They promote the capacity of the family to support their child's learning as part of everyday routines and to ensure the inclusion of children in mainstream settings with their peers.

Who:

National early supports are delivered by approved and registered Lead Practitioners. Lead Practitioner organisations who can provide a transdisciplinary approach, with a breadth of disciplines to support the Lead Practitioner, would be highly suitable. This would also prevent a fragmented approach to service delivery, contracting and funding.

The Lead Practitioner works with families to understand their child's strengths, needs and identify what supports are needed. Under a transdisciplinary approach the Lead Practitioner would play the primary role in coordinating and then delivering most (if not all) of the support. The Lead Practitioner would deliver supports from within their scope of practice and some direct intervention strategies from outside their discipline with supervision and support from other relevant professionals.

The Needs Assessment (some children may already have completed one as part of an access request) gives the Lead Practitioner a strong indication of what type and level of early supports are needed. An abridged version can be used to understand the need of the child and family if a Needs Assessment hasn't already been completed.

What:

The Lead Practitioner will work in a family-centred way to understand what is needed for the child and family.

The Lead Practitioner may work directly with the child and family or involve them in group sessions or workshops with other children and families. There should be a range of approaches to flexibly respond to need and evidence of what works. These approaches must be aligned with the best practice principles.

The supports may include:

- Working directly with children and families to identify and respond to their needs and priorities.
- Assisting families to support their children's development in everyday activities like meal and bath time and visits to the playground.
- Workshops for families on supporting child development or transitions such as communication or starting school.

- Supporting childrens' participation and inclusion in early childhood education and care and education through a capacity building approach.
- Building family confidence, resilience and self-advocacy skills.
- Providing families and other caregivers with resources, information and advice on activities and adjustments for development and inclusion.

When:

An assessment of need by the Lead Practitioner (or by the Needs Assessor if the child has tested access to the NDIS) should give an initial recommendation on whether supports are needed for a shorter or longer period of time. There should be no arbitrary cap on the length of supports. Similarly, the intent is not for early supports to be fully open ended.

If the child becomes a participant the early supports will stop.

Where:

Early supports must be delivered in close collaboration with other mainstream supports. This should be in part through more supports being delivered in natural settings and in part through early supports leaning more into mainstream services.

There are options for how government achieves closer integration. An approach may be to co-locate or deliver early supports in existing community infrastructure such as Integrated Child and Family Centres (where they provide natural settings for children). Using existing community infrastructure as a hub for early supports could provide place-based benefits even under a national approach. This should be balanced against the inconsistent availability of suitable community infrastructure across Australia and whether these locations provide truly natural settings.

Discrete and place-based models

In addition to the national model, there should also be discrete and place-based models of early supports. This is to allow for new approaches that are evidenced based to be trialled and scaled. It also allows for a specific place-based model to be used in areas where a national model isn't suitable (such as remote or very remote locations) or there are unique opportunities available (such as working jointly with a mainstream service or a community controlled organisation).

Discrete models of early supports provide a mechanism for government to trial and evaluate different approaches to early supports for children and families with emerging developmental concerns so best practice models can be tested before being scaled (where it is found they are beneficial and cost-effective). Approaches that are successful can then be integrated into the national model. This should create a continuous improvement loop where the national model is refreshed to align with contemporary practice as it emerges.

There may be evidence-based approaches trialled for child development generally, or for specific disabilities, demographics or cultures where a more tailored approach will deliver better outcomes.

The Telethon Kids Institute's Inklings Program is an example of a discrete approach that is evidence-based and is undergoing further trialling to better understand its benefits. This is a necessary step before a model like this could be expanded nationally.

> ### Case Study 1: Inklings Program example of discrete early supports
>
> The Inklings Program is a ten week program for babies and toddlers between 6 to 18 months old who are showing early differences in their social interaction and communication development. This leverages a critical window of development for children.
>
> The program captures short videos of families interacting with their baby. With the support of a practitioner, families are assisted to understand the different ways their baby communicates their thoughts, feelings and needs. At the end of the session, families are supported to develop a plan to incorporate the messages from the session into daily routines.
>
> Inklings has been shown to have positive impacts through a successful randomised control trial with around 100 families and children.[227]
>
> The Australian Government has budgeted a total of $22.1 million over four years on two pilots of pre-emptive early support projects for children with early signs of autism. One of these trials is the further implementation of Inklings with 700 children in Western Australia.[228]

Place-based initiatives typically target all children in a community. These approaches are often used in locations experiencing disadvantage where a more holistic approach is needed to address a breadth of challenges.

They can also be used in areas where a more specialised approach is required, either where a national model isn't suitable or there are unique benefits available.

In any scenario, a key requirement of a place-based approach is government working together across levels and departments. This provides strong integration benefits for children and families.

> ### Case study 2: Examples of place-based supports [229]
>
> **Stronger Places, Stronger People Initiative**
>
> The Australian Government has partnered with states and territories and 10 communities across Australia to take a collective impact, community led approach to disrupting disadvantage. Stronger Places, Stronger People is a place based approach that recognises the expertise of local communities.
>
> Initiatives span multiple locations across Australia including Logan, Rockhampton, Gladstone, Bourke, the Macleay Valley, Mildura, Burnie, the Far West Region of South Australia, the Barkly Region and Gove Peninsula.
>
> The initiatives include:

- A local project team in each community, responsive for planning, engagement, measurement and evaluation, joint-decision making, governance and local action

- A local community leadership group, who support the community in developing their strategy and plan

- Capacity building support to enable the project team to develop the skills necessary to implement plans

- Participation in a Partnership Exploration Process, designed to develop a shared understanding of practice, plan and confirm commitment from all partners

- A National Leadership Group which brings together leaders from communities, business, philanthropy, academia and service delivery, as well as representatives from Governments.

The aim of the initiative is to demonstrate how place based, collective impact approaches can support improved outcomes through locally tailored and evidence driven solutions to local problems, in partnership with local people.

First 2000 Days approach[230]

Brisbane South Primary Health Network, partners and Logan community leaders have collaborated to establish a local and targeted approach to supporting children in the first 2000 days. It covers Brisbane south areas identified as high-risk communities for child developmental vulnerability.

The First 2000 Days involves:

- Community led, place based and culturally inclusive maternity care

- Sustained nurse home visiting

- The Thriving and on Track Program where developmental issues are being identified early and families are receiving timely early intervention support

- Participation in supportive early childhood environments, such as playgroups

- Supporting families as children start school

- Community Connectors to support families to navigate the child health system and provide wraparound support.

Supports are delivered in trusted community hubs, family homes and local childcare centres and schools. Supports span from the antenatal period to when children are five years old. The purpose of this program is to better support children and families living in an area with higher rates of disadvantage through a critical developmental window.

Outcomes have included better ante-natal care, increased parenting ability, confidence and coping through implementing the right@home sustained nurse home visiting program, and increased health assessments in child care centres and participation in kindergarten.

Remote Early Childhood Services model in the Kimberley (Kimberly Aboriginal Medical Service)[231]

An early childhood intervention model in the Kimberley region of Western Australia that uses a service model that has been designed with community and for community. It provides support from birth to seven years

The program employs allied health staff who provide up to five sessions per term for children. The program also employs family support workers, who act as a cultural liaison for allied health workers coming into community. It also assists with referrals to obtain diagnoses as required and / or connection with information gathering and access requests for the NDIS

The model supported around 250 Aboriginal children, with only approximately 50 of those needing to be referred on to NDIS plans (around one-in-five), due to successful early intervention.

Support for families of children with developmental concerns or disability

In the future, communities and families will be better supported through widely available capacity-building programs (including for siblings) which include information, education, connections to other families and family leadership and empowerment. This should allow them to learn at their own pace, over time with planned and sustained information during the early years.[232] This should align with the broader approach to the proposed capacity building reforms (see Action 1.3).

This recognises the importance of investing in the family and enhancing their skills and confidence to meet the needs of their child. Well supported families lead to well supported children.

This also recognises that 'children learn most in the environments in which they spend most of their time, and not in specialist intervention sessions: what happens between formal sessions is when the majority of learning takes place, and not in therapy sessions: children learn from their natural caregivers, whether we want them to or not.'[233]

This will also be underpinned by support from Navigators for families who should provide access to information, provide advice and help families find and access supports across mainstream and foundational systems and the NDIS (see Recommendation 4).

The approach to designing these capacity building supports for families is set out in further detail below.

Information, education, connections and family leadership and empowerment

Family capacity building initiatives should at least cover the following three aims: [234]

- To help families understand the primacy of their role and of other natural caregivers in supporting their child's learning and development
- To provide families with the necessary skills, confidence and support to empower them to raise their children using contemporary approaches to disability

- To support families to understand the importance of ensuring their child lives a valued and included life in the same way non-disabled peers do.

We heard that there is not a one-size-fits-all approach to achieving these aims. There will need to be a suite of different offerings that reflect different needs and preferences in the community.

What this suite of offerings includes should be determined through a strategic approach through the overarching Foundational Support Strategy (Strategy) which should be developed by the Australian, state and territory governments. See Action 1.2 for more detail on how the Strategy should be developed and its necessary components. The exhibit below provides an overview of how this can be linked to family capacity building initiatives.

Box 3: Strategic approach to identifying capacity building supports

Identifying evidence-based capacity building supports for families of children with developmental concerns or disability will need to be guided by the Strategy.

A critical element of the Strategy will be the development of an outcomes framework. This will need to be appropriate for families of children with developmental concerns or disability (along with other people with disability). The development of the outcomes framework will provide a structure to begin to identify the highest priority areas of need and a theory of change for the necessary supports to respond to need.

This effectively provides a strategic investment framework that gives guidance on the type and volume of different supports that are required. This is a critical piece to avoid a repeat of the proliferation of many small time-limited projects funded through the ILC program. Investments must be more strategic in the future.

It is also essential to build on high-quality programs that have been developed across various government funding streams, particularly those that have been evaluated and/or have been co-designed. These programs must still be consistent with the strategic approach described above. Funding under a previous program should not mean automatic continuation.

The future capacity building program needs to be designed carefully with families to ensure the process is family and child centred and supports best practice. It should be informed by other experts in child development and capacity building program delivery and representative organisations. The design of the model has key dependencies with the work to develop the early supports approach and should be designed through an integrated approach.

A high-level overview of the potential future model is provided below.

Box 4: A potential future capacity building model for families

Family capacity building supports should be easily accessible through multiple channels and available in all areas, regardless of residency or NDIS status.

Navigators may recommend capacity building supports for families who have children with developmental concerns or disability. Families may also approach family capacity building organisations directly to participate in a session or activity they are delivering. There should also be information available online for families.

Family capacity building supports are based on the best practice principles and are rights based. They promote building the capacity of the family to support the inclusion and participation of their children in mainstream settings with their peers.

Who:

A network of organisations will be required to deliver best practice family capacity building supports.

Locally based organisations are well placed to deliver locally connected information and peer support models. However, they may not necessarily be experts in evidence-based family capacity building or be able to provide an integrated offering of multiple elements of family capacity building. This means that a network of organisations will likely be required. There should be mechanisms established to enable sharing of information and resources such as communities of practice across the network.

There should be a centralised approach to developing a minimum level of information to be shared with families. This is to ensure consistent information is provided to Navigators and Lead Practitioners, as well as to NDIA staff who are engaging with families of participants.

We also heard that there needs to be infrastructure such as communities of practice between organisations to support the delivery of high quality capacity building supports.

What:

Family capacity should take a range of forms and include:

- Information.
- Education.
- Connections to other families, including siblings.
- Family leadership and empowerment.

Workshops or peer support sessions should predominately be group-based. There may also be more individualised peer support based on need. On the whole, these family capacity building supports aren't intended to be an individualised model.

When:

Families of children with developmental vulnerabilities, concerns or disability may opt-in at any time.

They may be referred by a Navigator to family capacity building supports. This is likely to be one of the first referrals a Navigator will make for a family.

Where:

There will need to be a range of delivery models reflecting whether information, education, connections to other families or family leadership and empowerment is being provided.

Workshops or peer support sessions will need to be offered as a mix of online, video conferencing and in-person channels. This should reflect the preferences of those expected to participate.

Where it is in person, it should be embedded in communities and located at the natural places families visit, learn and play. Examples of this include community centres, maternal and child health centres, integrated child and family centres, early childhood education and care settings or schools.

2.9.4. Action & Implementation Details

Action 1.12: National Cabinet should agree to jointly invest in early supports for children with emerging development concerns and disability

Australian Governments, through their Foundational Supports Statement of Intent, should commit to build up over time a joint investment in early supports for children with emerging developmental concerns and disability. This is a key element of a proposed continuum of mainstream, foundational and specialist supports for children with disabilities (see Recommendation 6). It should include support from a Lead Practitioner to help children who are not eligible for the NDIS to build their skills and participate in everyday activities. The Lead Practitioner should provide families with information about child development, building their confidence and knowledge to support their child in everyday routines. This should be in addition to the proposed capacity building program (see Action 1.8). It should also include implementing and evaluating a range of other early support models. The delivery of these early supports should be closely linked to and integrated with mainstream services, particularly education and early childhood services.

Implementation detail:

- The Department of Social Services must complete, as a priority, Action 1.1 of the Early Childhood Targeted Action Plan to understand the support pathways and gaps in the early childhood service system for children with developmental concerns by jurisdiction.
- The Australian government should immediately repurpose the funding provided for Early Childhood Partners and provide additional funding to deliver an early supports foundational service offering.
- Australian governments should specify the mix of early supports for children with developmental concerns and disability they will fund over the next 3 years and update this annually, based on findings from the NDIS Evidence Committee (see Action 23.2).
- Australian governments should trial and establish a new and expanded national early supports offering for children with developmental concerns and delay. The future early supports model needs to be designed carefully with families to ensure the process is family- and child-centred and supports best practice. It should be informed by other experts in child development, service delivery and representative organisations
- Australian governments should trial and evaluate a range of early support models for children with developmental concerns and delay. These may include:

  - Support for infants showing early behavioural signs of autism (such as Inklings).

  - Place based supports, in particular for children in remote and very remote communities.

  - Supports specifically delivered by and for First Nations communities.

- There should be a commitment from Australian governments that new models of early supports for children with developmental concerns or disability should be first trialled, before they are progressively scaled up. Only those with positive impact evaluations that have been shown to improve outcomes and are cost effective should be scaled.

These actions should be supported by robust evaluation mechanisms that are designed with families to ensure supports are person-centric and effective for the families they are aimed at.

Action 1.8: National Cabinet should agree to jointly invest in a capacity building program for families and caregivers of children with development concerns and disability

Australian Governments, through their Foundational Supports Statement of Intent, should commit to build up over time a joint investment in a capacity building program for families and caregivers of children with emerging developmental concerns and disability. Communities and families will be better supported through universally available family programs which include information, peer support and creating and implementing a vision for their child for a valued and included life. This will mean families have access to timely support, be empowered with information and resources and connected with other families so they can build skills and confidence to support their child. This should be underpinned by mainstream service systems

building workforce capacity to identify developmental concerns and disability, and greater support from Navigators for families (see Recommendation 4).

Implementation detail:

Investment in this program should be guided by the Foundational Support Strategy (see Action 1.2). Investment in individual capacity building supports, such as self-advocacy, peer support and supported-decision making should complement the proposed Information and Advice/Individual Capacity Building initiative (see Action 1.3).

- The Australian Government with states and territories should establish and administer a new family capacity building program. The program should:

  - Be inclusive of all families and intersectionality

  - Be accessible and safe for families and caregivers irrespective of NDIS status, location or identity

  - Provide support early in the life of their child and continue across key developmental ages and stages (as needs change), including as they adjust following diagnosis of developmental delay or disability

  - Be evidence based and outcomes focused

  - Be designed with families and carers

  - Take a holistic view of what a good life looks like for children and is based on the social model of disability.

- The following should occur to support successful implementation:

  - Ensure organisations receive funding under medium-term arrangements of up to and preferably five years. There should be options to extend arrangements only where they are found to be high quality and effective (ideally evaluated).

  - Establish dedicated funding streams:

    o For national and statewide supports and initiatives. This should support greater consistency and coverage at a national and state level. This should encourage the formation of consortia, cooperatives or sub-contracting arrangements to allow smaller organizations to participate at a national and state level.

    o For local supports and initiatives. This should be focused on addressing community level needs within a nationally consistent framework.

    o For trials of new evidence-based approaches that need further testing before being suitable for scaling at a national level.

  - Establish focus areas to determine funding priorities across the initiative, these could include supports that address specific needs of particular disability groups, intersectional groups, First Nations, culturally and linguistically diverse, or remote and very remote

areas. It could also focus on specific elements of the family, such as father or siblings. These should be determined through detailed needs analysis.

- Develop an outcomes framework that tracks, reports and measures outcomes for families and carers. The framework will be reported against publicly on a yearly basis. The framework should be aligned with the proposed new Disability Supports Outcomes Framework (see Action 23.1).

- These actions should be supported by robust evaluation mechanisms that are designed with families to ensure supports are person-centric and effective for the families they are aimed at.

2.10. Adolescents and young adults are not supported well to transition to independence

Adolescence and young adulthood is a critical life stage which involves key transition points. This stage impacts on outcomes later in life and economic and social participation. It can also be a time when mental health issues emerge, including signs of more significant psychosocial disability.

We use the terminology of adolescence for the phase of life between childhood and adulthood, roughly between the ages of 10 to 19 and young adulthood to refer to the period of ages 19 to 21. We believe this is an important approach to ensure there is not a cliff where support falls away after early childhood.

Adolescents and young adults with disability continue to fare more poorly in comparison to their non-disabled peers across a range of indicators including educational and post-school outcomes, employment, income and independent living.[235]

In the future, there should a wider range of foundational supports outside the NDIS for adolescents and young adults to prepare for and manage key life transition points such as secondary school, employment and living independently. This includes capacity building supports across supported decision making, self-advocacy, peer support and leadership development. This should complement the broader capacity building reforms outlined in Action 1.3.

There should also be more support available from Navigators (see Recommendation 4). Navigators should play a key role in supporting people with disability and their families during critical life transition points, such as education, employment and housing and independent living. They are expected to have specific expertise working with young people to recognise the number of life transition points that occur during this time.

They should help navigate these transitions and importantly help to build awareness and capacity with participants and nominees before reaching these critical periods. They will be a key referral point for the capacity building supports described above.

The combination of foundational capacity building and navigation supports should mean that adolescents and young adults with disability are supported during the most challenging times and are well prepared to enter adulthood living valued and included lives. This has lifelong benefits.

2.10.1. There is not enough support that recognises the adolescence period lays the foundations for outcomes later in life

Adolescence and young adulthood is a period when brain development is continuing. It is a key period of frontal lobe development and synaptic pruning. Adolescence and young adulthood is a developmental phase for acquiring the assets for later health and wellbeing.[236]

It is also a period of major life transitions, from primary to secondary school, from being dependent to becoming independent, moving towards finding employment or participating in further education or training, and/or moving out of the family home. As mentioned, it can also be the period where mental health conditions begin to emerge, including more significant psychosocial disabilities.

> *"…as individuals progress into their teenage years and young adulthood (ages 13 to 25), they experience profound life transitions. These transitions include the development of identity, autonomy, and the establishment of personal values. Neurodevelopmental theory underscores the importance of these transitions in shaping an individual's overall well-being and functioning". – Children and Young People with Disability Australia[237]*

These factors combine to mean it is a critical period to ensure adolescents and young adults are prepared and well-supported.

> *"It is crucial to have youth-friendly and age-appropriate supports during this key developmental stage, particularly at key transition moments. This has the potential to save expenditure over a lifetime as adolescence is the second 'developmental window' for intervention having lifelong benefits." – Youth Disability Advocacy Service[238]*

The importance of early intervention during this critical period has been recognised through a complementary program in the work of Headspace, the National Youth Mental Health Foundation. Headspace supports adolescents and young adults with mental health, physical health, alcohol and drug services, as well as work and study support. Their aim is to help young people get back on track and build their capacity to manage their mental health in the future.[239]

We heard from families of adolescents and young people directly about their experiences during this period of change and development and the supports they currently have access to. There was a clear need to be more responsive and innovative in how young people are supported to transition to independence. Importantly, we heard that far more support is required to find, participate and sustain further education and employment.

We also heard about the impact of falling between the gaps of disjointed service system. Existing support from LACs and Support Coordinators wasn't considered to be helpful assisting young

people to navigate to effective supports. There is a desire for much clearer navigation roles and advocacy support for young people.

Education

Transitions from primary school to secondary school are difficult for any young person. It is a time when school structures change dramatically. These adjustments are particularly challenging for people with disability.

Young people with disability face the additional challenge of not being consistently included at school (see Section 3.5).[240] The provision of reasonable adjustments to support young people at school is protected by law. However, young people with disability still face barriers to be included at school and can face barriers to accessing and maintaining enrolments.[241] This can put young people with disability onto a separate trajectory from their peers. Inclusion Australia describe decisions to go into a segregated learning environment as the start of a 'polished pathway' where people with intellectual disability then face significantly lower barriers to future segregated environments in housing and employment.[242]

> *"Issues frequently observed by YDAS include a lack of understanding amongst these systems and support services of their obligation to provide reasonable adjustments for disabled young people. There is a predisposition to assume that NDIS will provide support for disabled young people even when this is within the scope of the support service. In some cases, this can lead to young people being unable to access mainstream services, or remaining in unsafe situations or without essential support for months." – Youth Disability Advocacy Service[243]*

Secondary school is also the critical period for young people to begin to consider and prepare for their career aspirations and further educational or employment options. However, these same opportunities are not being made available to young people with disability.

In 2019, Children and Young People with Disability Australia surveyed just over 100 individuals to understand the experience of senior students with disability and their families with career planning and post school options. Most respondents were families of young students with disability, with students with disability and advocates, teachers and school staff also responding.

Four out of five (80 per cent) of families and young people with disability reported that their school did not provide support or appropriate information about career planning. Less than half (43 per cent) of students reported having access to work experience, this was despite it being identified as the most common form of support provided to students to prepare for employment. Just over half (54 per cent) reported that they did not receive adequate support to plan for their future. Almost two-thirds (60 per cent) felt that the school did not have high expectations of the student with disability regarding employment or further education after school. [244]

We have similarly heard that planning in the upper years of secondary school can be characterised by low expectations for young people with disability. This is particularly the case for students with

intellectual disability. Arguably having lower expectations means that there is less effort and investment made to build the capacity of the young person for their future.

> *"I will be seeking NDIS support to help train and equip me as I leave school as I am not certain yet whether I will go straight into a job or do more study. I hope the NDIS will support me to explore those options. I don't get that help at school. My school pushes a lot for University after school. I would like to know what else is available especially due to having a disability." – Young Person[245]*

Years 9 and 10 can be a 'sliding doors' moment for young people with intellectual disability. This is the time where their non-disabled peers are receiving career counselling and choosing subjects to prepare for tertiary education and employment. However, young people with intellectual disability don't experience these same opportunities. Lower expectations means that they receive less support and will often leave school without a complete education or not having completed work experience. This can also lead to being encouraged into other forms of segregation including moving to special schools, day programs or Australian Disability Enterprises.[246]

We have also heard that adolescents and young adults with disability continue to face significant barriers with post-school education. This furthers the challenges they have experienced through secondary school.

> *"I had to withdraw from my TAFE course before it started due to health issues and not being aware of ways courses could be adjusted to accommodate me. I would like to pursue a TAFE course but struggle with not knowing whether or not tertiary institutions offer the accommodations I would need to participate." – Young Person[247]*

Employment

Young people with disability are often excluded from work experience and employment opportunities taken up by their non-disabled peers while they are in secondary school.

This can be due to lower expectations and opportunities being offered. It can also be because many of the entry-level jobs for young people after-school or on weekends are demanding physically and/or require high social interaction with customers (such as those in hospitality and retail). These entry level roles also require the young person to take on additional workload on top of school, which can already be a significant workload for a young person with disability.

All of this means that young people with disability can have less work experience and are already at a disadvantage in the labour market when they leave school.[248] This puts young people with disability on a different employment and income trajectory from their peers. It also results in barriers to finding long-term sustainable employment.

There are a range of programs that provide employment support for young people with disability, including the School Leaver Employment Supports, the DES program, Transition to Work, as well as state and territory based programs. However, these programs are not well connected and there are many challenges with the approaches of these programs.[249]

Navigating these programs across different levels of governments and service systems is also difficult. This makes the job of maximising the support available, challenging for young people with disability and their families, particularly those with intellectual disability.

Supported decision-making

Many people with cognitive disabilities and complex communication support needs have experienced a lifetime of being denied the right to make their own decisions or have control over their lives.[250]

Decisions about adolescents are often framed as being made in their best interests, rather than involving the person in decision-making. This can limit their opportunities to develop and practice decision-making skills and navigate risk.[251]

Families of children with disability are not encouraged to take the same approach as other children who would begin receiving support for decision-making early in their lives and gradually be given more responsibility and exposure to risk as they age. This leads to adolescents with disability being provided far fewer opportunities to practice independence, experience autonomy, and engage in risk-taking behaviour when compared with peers without disability.[252]

Outcomes data for adolescent and young adult participants (aged 15 to 24) reveals that most are not involved in making decisions regularly and want more choice and control in their lives (Figure 13).[253] This is based on participant responses to choice and control over time who have been in the scheme for four years since 2016.

While this data is specific to participants, it highlights how significant this challenge is for this age group (even for those with support from an NDIS Plan).

Figure 13: Experience of choice and control amongst adolescent and young adult NDIS Participants (15-24) as at 30 June 2021[254]
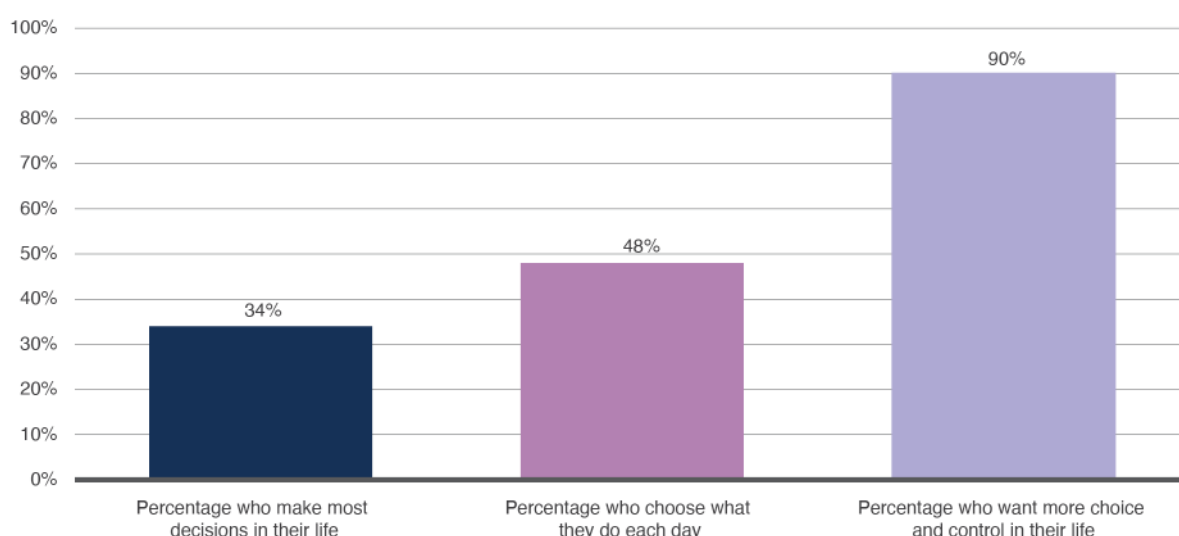
There are very limited supports for decision-making both inside and outside of the NDIS. A lack of specialist expertise and dedicated investments in this key area are the main factors limiting the availability of support for decision-making for young people.[255]

> *"When adolescents come of age at 18 and gain legal adulthood, the NDIS emphasises their autonomy in decision-making and plan management. Yet, this pivotal juncture lacks adequate specialised assistance. By flagging trigger points at such crucial moments, the NDIS can enable support and skill growth. This aid would encompass essential facets like defining objectives, selecting NDIS providers, liaising with the NDIA and medical experts, as well as fostering self-advocacy and informed choices." – Children and Young People with Disability Australia[256]*

The ILC Program has provided funding for some innovative capacity building for young people to grow their voice, self-advocacy and leadership skills. However, these programs face the same challenges of the broader program, that they are limited by the size and duration of the funding available. There is far more demand for these capacity building supports than currently available.

2.10.2. There should be far more foundational support for adolescents and young adults with disability aged 9 to 21 to prepare for and manage key life transition points

There should be a wider range of targeted foundational supports for adolescents and young adults with disability. Support during this critical developmental phase has lifelong health and wellbeing benefits.

The targeted foundational supports should include a range of capacity building supports that help adolescents and young adults to prepare for and manage key life transition points such as secondary school, employment and living independently. It should include capacity building supports across supported decision-making, self-advocacy, peer support and leadership development. These should complement the broader capacity building reforms outlined in Action 1.3.

This should be underpinned by support from Navigators. Navigators should play a key role providing support during critical life transition points for all people with disability and should have specific expertise working with young people to recognise the number of transitions that occur during this time. They would also be a key source of information and referrals to capacity building supports. Navigators should be locally connected to understand services and potential employers in a young person's community.

These investments should be cost-effective in the long-term. Investing in adolescents and young adults will put them on a trajectory to living more independent lives, having stronger education outcomes, and having higher rates of employment and income. This should provide cost savings across governments.

Capacity building

The breadth of the target age group means that a range of different supports will be required.

There should be a clear approach to meeting different types of need across life stages and transition points. There should be a tailored approach for supporting younger adolescents as they move out of early childhood through to beginning secondary school, during secondary school and beginning employment and living independently. These are simple examples and more work is required to better identify and differentiate need across age groups.

This means supports will need to cover different areas but will also require specific delivery approaches to reflect the needs and preferences of different age groups.

What this suite of offerings includes should be determined through a strategic approach through the overarching Strategy to be developed by the Australian, state and territory governments (see Action 1.2). Box 5 below provides an overview of how this can be linked to capacity building supports for adolescents and young adults.

Box 5: Strategic approach to identifying capacity building initiatives

Identifying effective evidence-based initiatives for adolescents and young adults with disability will need to be guided by the Strategy.

A critical element of the Strategy will be the development of an outcomes framework. This will need to be appropriate for adolescents and young adults (along with other people with disability). The development of the outcomes framework will provide a structure to begin to identify the highest priority areas of need and a theory of change for the necessary supports to respond to need.

This effectively provides a strategic investment framework that gives guidance on the type and volume of different supports that are required. This is a critical piece to avoid a repeat of the proliferation of many small time-limited projects funded through the ILC program. Investments must be more strategic in the future.

It will also be essential to build on high-quality programs that have been developed across various government funding streams, particularly those that have been evaluated and/or have been co-designed. These programs must still be consistent with the strategic approach described above. Funding under a previous program should not lead to automatic continuation.

This process will need to closely involve young people to ensure it is person-centred and responsive to need. It should be informed by adolescents, young adults, families, representative organisations, and other relevant experts (such as those with expertise in youth development, capacity building supports delivery, supported decision-making, education, employment and independent living). This should ensure foundational supports are designed with the people they aim to support and can be practically delivered.

A youth reference group should be established to play a central and consistent role in informing this strategic approach.

Future foundational supports for adolescents and young adults with disability who are not NDIS participants should include evidence-based initiatives for:

- Building decision making and self-advocacy skills.
- Empowering peer support programs for young people to meet other young people and build connection and community.
- Leadership skills development programs.
- Increasing work readiness and preparing for employment.
- Information, resources and education about transitioning to independence.

This should also include specific capacity building supports delivered by Lead Practitioners for adolescents and young adults with higher needs, including:

- Working directly with adolescents and young adults with disability to identify and respond to their needs and priorities.
- Supporting transitions such as moving between schools or starting a job.
- Supporting adolescents and young adults with disability participation and inclusion in education through a capacity building approach.
- Building confidence, resilience and self-advocacy skills.
- Providing resources, information and advice on activities and adjustments for development and inclusion.

In practice, this may mean the Lead Practitioner is responsible for leading small group sessions or working directly with the adolescent or young adult (including families). This will ensure a transdisciplinary approach, where the Lead Practitioner would play the primary role in coordinating and then delivering most (if not all) of the support.

Because these supports are for adolescents and young adults outside of the NDIS, the coordination role of the Lead Practitioner is expected to be smaller compared to children inside the NDIS (as there will not be NDIS providers to coordinate).

They should also work with key stakeholders from schools, tertiary education or potential employers and mainstream services to build their skills and capacity to support adolescents and young people in education and employment.

Organisations that are approved to provide Lead Practitioner supports in the NDIS are well placed to deliver these supports (see Action 1.12). They will be qualified allied health practitioners, developmental educators or early childhood educators.

These supports from the Lead Practitioner should be needs-based and short-term in duration. Those with higher on-going needs are expected to be supported within the NDIS. If the individual becomes a participant, the support from the Lead Practitioner will stop.

Section 2.9.3 provides further detail on potential approaches to using a Lead Practitioner organisation to deliver a transdisciplinary approach.

2.10.3. Action & Implementation Details

Action 1.13: National Cabinet should agree to jointly invest in programs and initiatives to support young adults with disability aged 9 to 21 to prepare for and manage key life transition points such as secondary school, employment and living independently

Australian Governments, through their Foundational Supports Statement of Intent, should commit to build up over time a joint investment in programs and initiatives to support young adults with disability aged 9 to 21 to prepare for and manage key life transition points. This should include support to help build the capacity of young people who are not eligible for the NDIS to transition to secondary school and remain engaged in education, and to prepare for employment by developing job-ready skills and confidence. It should also involve decision-support training programs to prepare for major life transitions (see Action 5.2). The delivery of these supports must be closely linked to and integrated with mainstream services, particularly education and employment.

Implementation detail:

Investment in this program should be guided by the Foundational Support Strategy (see Action 1.2). Investment in individual capacity building supports, such as self-advocacy, peer support and supported-decision making should complement the proposed Information and Advice/Individual Capacity Building initiative (see Action 1.3)

- In line with the Strategy, the Australian Government with states and territories should establish a suite of programs and initiatives to support adolescents and young adults. This should include evidence-based approaches for:

  - Building decision making and self-advocacy skills.

  - Empowering peer support programs for young people to meet other young people and build connection and community.

  - Leadership skills development programs.

  - Increasing work readiness and preparing for employment.

  - Information, resources and education about transitioning to independence.

- This should also include an approach to delivering needs-based and short-term capacity building supports that are provided by Lead Practitioners using a transdisciplinary approach, including:

  - Working directly with adolescents and young adults with disability to identify and respond to their needs and priorities.

  - Supporting transitions such as moving between schools or starting a job.

- Supporting adolescents and young adults with disability to participate and be included in education through a capacity building approach.

- Building confidence, resilience and self-advocacy skills.

- Providing resources, information and advice on activities and adjustments for development and inclusion.

- The Australian Government with states and territories should develop an implementation approach for the suite of programs and initiatives in line with the approach proposed in Action 1.8.
- These actions should be supported by robust evaluation mechanisms that are designed with adolescents, young adults and families to ensure supports are person-centric and effective for the adolescents and young adults they are aimed at.

3.   Inclusive and accessible mainstream and community services

- All Australians rely on mainstream services such as health, education and transport. Many also participate in programs and activities based in the community such as those run by community groups, non-government organisations, sporting clubs, local councils, employers, church groups and charities.

- Ensuring people with disability can use the same services and participate in the same activities as everyone else is a fundamental human right enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

- More inclusive and accessible mainstream services and communities will not only produce better outcomes for people with disability but can also reduce the need for specialist disability supports over time.

- Despite commitments in the first National Disability Strategy (2010-2020) and now the Australian Disability Strategy, many mainstream services remain inaccessible and do not meet the needs of people with disability. Many community programs, services and activities are also not accessible or inclusive of people with disability.

- The NDIS should operate within an ecosystem of services and service systems that work together to ensure people with disability can access the right mix of supports at the right time in a connected and inclusive way, not just the NDIS.

- Australia's approach to protecting, promoting and advancing the rights outlined in the UNCRPD and driving greater inclusion, including through legislation, has not been strong or comprehensive enough to ensure change at an acceptable pace or equally for all groups of people with disability.

- Current legislative approaches, such as the *Disability Discrimination Act 1992* (DDA), are largely reactive and do little to encourage active steps to prevent discrimination and promote inclusion.

- Complaints under the DDA have more than doubled between 2017-18 and 2021-22.[257] We have also heard concerns with how fit-for-purpose and contemporary Australia's approach is to disability rights, discrimination and inclusion legislation, including the current DDA. This was also a finding of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission).[258]

- There is Australian, state and territory government legislation promoting inclusion. However, a lack of comprehensive and integrated legislative frameworks across jurisdictions promoting inclusion is compounded by the lack of coordination across systems to support people with disability. This results in poorer life outcomes for people with disability including social, health and economic outcomes.

- The introduction of the NDIS has improved lives of people with disability. However, its often complex interface with many mainstream services has made navigating multiple systems even more difficult for people with disability. These complexities are further compounded by responsibilities and legislation being split between the Australian Government (NDIS) and state

and territory governments (who have primary responsibilities for many of the other service systems).

- The introduction of the NDIS has led to an underinvestment in time and resources on improving the availability and accessibility of mainstream services for people with disability, as all governments prioritised the NDIS.

- Attempts to clarify roles and responsibilities of mainstream service systems and the NDIS have not been effective. Roles and responsibilities outlined in the Applied Principles and Tables of Support (APTOS) have not translated into consistent and effective collaboration on the ground.

- A binary approach to the way NDIS and mainstream services work, under APTOS, has led to poor outcomes for many people with disability. There has been insufficient recognition that people with disability need supports from more than one system at the same time.

- This binary approach – together with the Australian Government being primarily responsible for the NDIS and states and territories for other services systems, except aged care - has led to responsibilities and funding arrangements becoming more and more contested, with poorer outcomes for people with disability.

- When issues occur at specific interfaces of the NDIS and mainstream services, this can create confusion and ambiguity for participants. At best this is frustrating and time consuming. At worst it can put the health, wellbeing and safety of people with disability at significant risk.

- Despite being the subject of repeated calls for change over the last ten years, the problems remain significant. We have heard about challenges that remain unresolved at the interfaces between the NDIS and the following systems, and therefore recommend particular action in these areas:

  - child protection

  - justice

  - hospitals

  - palliative care

  - mental health

  - school education

  - transport

  - aged care

- Rather than a binary approach, we recommend a more person-centred approach where systems reach into each other to provide more effective and coordinated support.

- To replace the APTOS, a multilateral schedule to the new Disability Intergovernmental Agreement should be developed. The multilateral schedule should clarify single system responsibilities and articulate shared system responsibilities, including interface specific working arrangements. Detailed Memoranda of Understanding between the National Disability Insurance Agency and particular mainstream services should be developed to agree jurisdiction-specific working arrangements that benefit people with disability

- Temporary arrangements put in place during NDIS transition in two key areas remain unresolved ten years later. Key aspects of the National Injury Insurance Scheme (NIIS) have not yet been implemented and some in-kind arrangements undertaken by state and territories on behalf of the NDIS remain in place long after transition has finished.
- Of the four originally proposed streams of the NIIS, only the motor vehicle and workplace accident streams were established. This has left significant gaps that push people into the NDIS. Arrangements between the NDIS and existing no-fault compensation schemes are also inconsistent, which can result in overlap with the NDIS and create additional stresses for participants and costs on the NDIS.
- In-kind programs are disability-related services funded by the NDIS but delivered by state and territory governments. The cost of these supports is then counted as state and territory in-kind contributions to their shares of overall scheme costs.
- In-kind arrangements are inefficient and were intended to only be a transitional arrangement. However, delivery of personal care in schools and specialist school transport schemes continue to be delivered by states and territories on behalf of the NDIS. While this has ensured service continuity, it has disincentivised reform and constrained choice. It has also led to failures to invest in these programs or ensure a nationally consistent standard across jurisdictions.

Recommendation 2: Increase the scale and pace of change in mainstream and community inclusion and accessibility and improve the connection between mainstream services and the NDIS

🗐 Legislative change required

To increase mainstream and community inclusion and accessibility...

- 🗐 Action 2.1: The Attorney General's Department, with the Department of Social Services and the states and territories, should develop a unified and contemporary approach to disability rights, discrimination and inclusion legislation.
- Action 2.2: All Australian governments should improve the recognition and responsiveness of government services to culturally and linguistically diverse concepts of disability and care by investing in targeted research, education material and capability building for government organisations and staff, professionals and providers who deliver government services.
- 🗐 Action 2.3: The Department of Social Services with relevant agencies should develop and trial a mechanism to publicly communicate the performance of current Disability Standards under the Disability Discrimination Act 1992.
- 🗐 Action 2.4: All Australian governments should incorporate Disability Impact Assessments into new policy proposal assessment processes.
- 🗐 Action 2.5: All Australian governments should take steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools.

To improve the connection between the NDIS and mainstream services...

- ▤ Action 2.6: National Cabinet should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities.
- Action 2.7: The Department of Social Services, working with other Commonwealth agencies, state and territory disability agencies and the National Disability Insurance Agency, should implement a priority work program to improve coordination between complex mainstream settings and the NDIS.
- Action 2.8: The National Disability Insurance Agency and the Department of Education, with state and territory education and disability agencies, should develop a plan to better connect the NDIS and school education systems and improve educational outcomes for children with disability.
- Action 2.9: The Productivity Commission should develop an NDIS transport policy that better meets the mobility needs of participants.
- Action 2.10: The Australian Government should develop a national strategy to improve the quality of the disability ecosystem for First Nations people with disability.
- ▤ Action 2.11: The Australian Government should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary.
- ▤ Action 2.12: The Australian Government should implement legislative or process change to allow access to the NDIS for Disability Support for Older Australians program participants.
- Action 2.13: All Australian governments should agree as a matter of priority to expand universally available child development checks, to ensure the early identification of children with developmental concerns and disability and enable early intervention.
- Action 2.14: State and territory governments should commit to and implement the general accidents stream of the National Injury Insurance Scheme.
- Action 2.15: The National Disability Insurance Agency and the Department of Social Services, working with state and territory governments and other relevant Commonwealth agencies, should update current arrangements governing the interaction between the NDIS and compensation schemes to reduce overlap and improve participant experiences.
- ▤ Action 2.16: The Disability Reform Ministerial Council should agree to cease the use of 'in-kind' arrangements in the NDIS.

3.1. Mainstream services and communities are not fully inclusive and accessible for people with disability, limiting social and economic participation

Inclusive and accessible mainstream services and communities provide better outcomes for people with disability and reduce the need for more specialist disability supports over time.

We acknowledge the significant body of work already undertaken across governments to make mainstream services and communities more inclusive and accessible for people with disability, Australia's Disability Strategy (ADS) and recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission).

We seek to build upon this work and highlight ways to ensure the entire ecosystem can work more effectively together. This should create equitable supports for all people with disability as well as ensure a sustainable NDIS. This includes looking at the role of intergovernmental agreements, legislation, disability action plans and other mechanisms such as investing in research to improve inclusion and accessibility for all people with disability.

3.1.1. Inclusive mainstream services and communities benefit all Australians

All Australians rely on mainstream services such as health, education and transport. Many also participate in programs and activities based in the community such as those run by community groups, non-government organisations, sporting clubs, local councils, employers, church groups and charities.

All Australians benefit from more inclusive and accessible mainstream services and community programs and activities. For example:

- Accessible public transport and services makes it easier for everyone to use public transport
- Inclusive and responsive schools make it easier for all children to learn
- More inclusive and accessible workplaces make it easier for all Australians to find and keep meaningful work
- More inclusive sporting clubs and recreational activities will help all Australians, regardless of their ability, to participate in their preferred activities and make friendships.

Ensuring people with disability can use the same services and participate in the same activities as everyone else is a fundamental human right. This is outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which includes people with disability having the right to live independently and take part in all aspects of life.[259] Australia is a signatory to the UNCRPD. Its commitment is reflected in a range of policies, program and legislation, including ADS, *Disability Discrimination Act 1992 (DDA),* and state and territory disability legislation.

Commitment to the UNCRPD is also reflected in the commitment of all Australian governments to the NDIS. But the NDIS on its own is insufficient to realise the inclusive vision of the UNCRPD. The realisation of the rights outlined in the UNCRPD can only be achieved when the Australian community is free from discrimination, inclusive and accessible to people with disability and ensures individuals can live with dignity, equality and respect.

The NDIS was designed to operate within an ecosystem of support, this includes mainstream services. Every government in Australia agreed to make their mainstream services more inclusive and accessible before the roll out of the NDIS. This was set out in the first National Disability Strategy, which ran from 2010 to 2020.[260] However, progress has been slow as governments prioritised the rollout of the NDIS.

> *"More wrap around support with health and education. I know NDIS doesn't support this, but first nations people have a hard time accessing these supports at the best of times." – First Peoples Disability Network[261]*

There is now a pressing need to complete design and implementation of the ecosystem. This includes the community-wide rollout of inclusive and accessible mainstream services and foundational supports to sit side-by-side with individualised supports funded by the NDIS.

3.1.2. People with disability continue to face discrimination and barriers accessing mainstream services and participating in their communities

Australia's approach to inclusion has not been strong or comprehensive enough to drive change at an acceptable pace or equally for all groups of people with disability.

> *"People do not understand my disability and I constantly am being discriminated against for that." – Person with disability [262]*

In 2019-20, 1 in 5 (22 per cent) people aged 15 and over with disability experienced some form of discrimination, compared with 1 in 7 (15 per cent) without disability, with a majority experiencing disability discrimination.[263] Complaints under the DDA have more than doubled between 2017-18 and 2021-22.[264] Additionally, in 2021-22 the DDA had the highest number of complaints regarding discrimination in the provision of goods, services and facilities (52 per cent of all complaints).[265]

First Nations people with disability, women, culturally and linguistically diverse and LGBTIQA+SB communities face intersectional discrimination, which can be compounded by institutions that do not consistently understand or consider their experiences (see Action 2.10). A systematic review of First Nations voices in disability support services funded by the National Disability Research Special Account in 2021 found that the intersection of racist and ablest attitudes can also contribute to the economic exclusion and high levels of socio-economic disadvantage of First Nations people with disability.[266] This is heightened for First Nations women with disability due to the addition of gendered discrimination in broader society.[267]

Culturally and linguistically diverse people with disability also face additional barriers to accessing culturally appropriate disability supports due to the intersection of language barriers and varied understandings of disability and care. This is amplified for people of colour from culturally and linguistically diverse backgrounds, especially women who do not have the same access to social capital, cultural safety and resources.[268]

> *"Disability is often interpreted differently across cultures..." - National Ethnic Disability Alliance [269]*

Applications of intersectionality across the disability ecosystem and relevant legislation such as the DDA go some way to recognising that people with disability experience interlinked discrimination that amplifies experiences of marginalisation and exclusion.

Discrimination can negatively impact social and economic participation, exacerbating socio-economic disadvantage and poverty. As noted above, the proportion of people with disability (aged 15 and over) in the labour force who are unemployed is double the proportion of people without disability, and the unemployment gap between people with disability and people without disability widened between 2012 and 2018.[270] Four in ten (39 per cent) people with disability aged 15 to 64 are also not satisfied with their local community, compared with 27 per cent of those without disability.[271]

The Disability Royal Commission also highlighted cultural, language and other differences creates barriers to the full participation and inclusion of all people with disability, across all aspects of life.

3.1.3.   Disability legislation should be reviewed and improved

The Australian Government, and many state and territory governments have disability discrimination and disability laws. This highlights the importance many governments place on protecting the rights of people with disability. However, given some inconsistencies in these approaches, there is an opportunity for a more coordinated, consistent and effective approach to tackle discrimination.

The DDA is intended to protect all Australians with disability from discrimination in many public domains, including employment, education, getting and using services and accessing public spaces.[272]

We have heard concerns about how fit-for-purpose and contemporary Australia's approach is to disability rights, discrimination and inclusion legislation, including the current DDA.[273] Key stakeholders have highlighted the limitations with the DDA, including as part of the NDIS Review, the Disability Royal Commission and the review of the DDA by the Productivity Commission in 2005.[274]

The DDA largely relies on reactive mechanisms to address discrimination, such as complaints processes.[275] As a result, more time is spent on managing and responding, rather than preventing discrimination. It also means if a person with disability experiences discrimination, the onus is on the individual person, families or carers to bring a complaint or legal action to enforce their rights.[276]

We recognise that legislation exists in other jurisdictions, and that Victoria is currently reviewing their *Disability Act 2006*. Victoria's review aims to take a more contemporary and proactive approach to disability inclusion, that supports the vision of a barrier free Victoria for all people with disability. The exposure draft explored elements such as a positive duty to promote inclusion, establishing a responsible Inclusion Commissioner to monitor progress, universal design and considerations of intersectionality and ableism.[277]

There are also concerns that state and territory legislation may be unintentionally leading to uncertainty. People may be unsure of which jurisdiction is responsible for a given aspect of disability discrimination law. In addition, providers and organisations might not know whether compliance with one set of laws is compliant with all relevant laws.[278] The Australian Human Rights Commission has recommended a more proactive approach to preventing and reducing disability discrimination.[279] This would include reforms to the DDA, as well as a holistic human rights Act in Australia, which would improve and reconcile inconsistency across the various legislative frameworks for discrimination.

> *"Australia's discrimination laws are outdated and difficult to use. Some of these laws have remained substantially untouched since they were introduced over 30 and 40 years ago. They do not respond to the challenges of modern life and are often unsuccessful as a means of remedying discrimination, let alone preventing it." –* *Australian Human Rights Commission* [280]

There is an opportunity to modernise and improve legislation governing disability accessibility and inclusion. This should take into consideration the DDA but could be broader and include looking at powers relating to mainstream service standards and disability action plans.

The Disability Royal Commission has also highlighted the need for a stronger and more comprehensive legal framework, including a Disability Rights Act, which would protect and promote the human rights of people with disability and shift the legislative burden away from individuals with disability reporting discrimination.[281]

3.1.4. Disability standards provide an opportunity to improve service quality and accessibility

The DDA enables the creation of Disability Standards and Guidelines, which provide more detailed information on the rights of people with disability and the obligations of organisations and providers when providing a given service or support. Current standards include:

- *Disability Standards for Education 2005* (standards for education) – which cover enrolment, participation, curriculums, support, and elimination of harassment in most educational organisations [282]
- *Disability Standards for Accessible Public Transport 2002* – which cover accessibility requirements for public transport operators, including trains, buses, taxis, and airlines[283]
- Disability (Access to Premises — Buildings) Standards 2010 – which cover accessibility for public buildings.[284]

Standards are agreed requirements for a product, process, or service that can be used to improve safety, efficiency, and performance. Good standards can offer comparability, certainty and a proactive mechanism for quality service provision.

As highlighted by the Royal Commission in Aged Care Quality and Safety, standards are key to improving consumer knowledge and choice, which can put pressure on facilities and create incentives to improve outcomes.[285]

However, for standards to be effective they must be comprehensive, easy to understand and enforced. For example, there are many exceptions to the standards for accessible public transport. The accessible public transport standards are now being updated.

It is also important to note that some major standards affecting people with disability are not set through the DDA. For example, the minimum standards for accessible new housing, the Livable Housing Standards, are set through the National Construction Code. These are not enforceable, as it is the responsibility of states and territories to decide whether to include these standards in their relevant building standards and codes (see Action 9.11). This is confusing and undermines a comprehensive approach.

The Productivity Commission review into the DDA noted enforceable disability standards can play an important role in improving disability access and inclusion.[286] Feedback from people with disability, families and carers and the disability sector suggests current disability legislation and disability standards have not got the balance right between enforceability and compliance, reducing the effectiveness of these standards.

The importance of Australia rebalancing its disability standards was outlined in a review by the United Nations Committee on the Rights of Persons with Disability in 2019, which recommended that Australia:

> *"Establish and enact a national framework for mandatory compliance reporting of the Disability Standards for Accessible Public Transport, the Disability (Access to Premises-Buildings) Standards, and the National Standards for Disability Services." – United Nations* [287]

Given the critical importance of a good education to social and economic participation we believe that education standards present a particular opportunity for reform. The latest review of Disability Standards for Education, conducted in 2020, highlighted that:

> *"More people need to know about and understand the Standards [and] we need to make sure the Standards are followed." – Department of Education* [288]

The Early Childhood Targeted Action Plan (TAP) under the ADS has also identified the need to reform the Disability Standards for Education, in the form of broadening the Standards to include early childhood education and care.[289]

Currently it is difficult for parents and caregivers to assess how well an early childhood centre or school is performing in terms of inclusion and meeting educational standards. For example, a star rating or similar mechanism would mean the quality of early childhood and school facilities and practices could be known at a glance and could incentivise and encourage schools to continually improve their practices. It would also play a role in enabling a more accessible and inclusive education system, where the NDIS does not need to step in to fill gaps.

Incentives to deliver more accessible and inclusive mainstream services can be improved through making public the extent to which service systems and organisations meet or exceed transparent standards. There are examples of how to do things better from other policy areas, including:

- Food standards set in Australia and New Zealand ensure public health and safety and make sure the information people receive about food is comparable and consistent.[290] These standards are also enforceable, and those who contravene them face consequences.[291] Accordingly, Australia and New Zealand have a reputation for safe and high quality food.[292] This is important in two ways: it increases trust, and it means people can make more informed choices.
- The introduction of a star rating system as of December 2022 for residential aged care, following the Royal Commission into Aged Care Quality and Safety.[293] This star rating measures whether a residential aged care facility is complying with regulated standards, and to what level of quality it is delivering services. Although a lot of work goes on behind the scenes, someone can very easily see that a five-star aged care facility is preferable to a two-star facility. This creates positive incentives. If the two-star facility wants more clients, it will have to lower prices or raise quality.

Standards for disability accessibility and inclusion in mainstream services should set a clear, comparable and enforceable level of quality. This should be coupled with accessible communication that allows people to know just how accessible and inclusive these services are.

This should improve transparency, give parents and caregivers more information to assist them in making choices, and incentivise good practice in schools. It would push governments and their mainstream service systems to improve where they are falling short of community expectations and drive greater inclusion.

3.1.5. Disability Action Plans and Disability Inclusion and Access Plans can improve inclusion

Disability Actions Plans (DAPs, also known as Disability Inclusion and Access Plans or DIAPs in some jurisdictions) are key instruments under the DDA and state and territory legislation to reduce discrimination and promote inclusion and access. All governments, businesses and community organisations are expected, and in some cases required by law, to have a DAP.

We have heard from people with disability, the disability sector, and other key stakeholders that DAPs have not been effective in driving meaningful and inclusive change. The key issues that have been identified include:

- The lived experience of people with disability, families and carers are underutilised in development and management of DAPs
- DAPs are often regarded as a 'tick the box' exercise that may sit on shelves instead of changing practice
- Organisations often have limited incentives to complete and update DAPs, particularly non-government organisations (under the DDA)
- A lack of accountability or transparency for outcomes delivered

- A lack of comparability and consistency across, and in some cases within, jurisdictions
- Limited guidance and training to explain what good inclusive and accessible practices look like.

There are examples of how to do things better from other policy areas. This includes Reconciliation Australia's approach to supporting organisations to advance reconciliation and deliver tangible and substantive benefits for First Nations people, such as Reconciliation Action Plans (RAPs). Reconciliation Australia's approach includes the following key elements:[294]

- Reconciliation Australia reviews individual RAPs and provides strategic feedback to organisations.
- Provision of dedicated resources and guidance, including a RAP Framework which supports organisations to adopt a consistent and effective approach to reconciliation.
- Release of annual impact reports that detail the outcomes delivered from RAPs, including economic participation, economic opportunities for First Nations people and shifts in understanding of First Nations culture.
- Reconciliation Action Plans are created for a specific period, generally between 12 and 24 months.

Reconciliation Australia's approach is useful in informing potential reforms to reduce disability discrimination and to make mainstream services and communities more accessible and inclusive for people with disability. However, it is important not to conflate the experiences and needs of non-Indigenous people with disability and that of First Nations people with disability and their communities.

3.1.6. Governments should pay more attention to disability considerations when developing policy

Impact assessments are a valuable tool that can improve policy making by identifying the potential impacts of policy change, maximising its benefits and mitigating risks.[295] However, the use of impact assessments with a disability focus can be improved.

Governments in Australia use several impact assessment processes as an oversight mechanism before policy is agreed to ensure policy is rigorous and considers all relevant outcomes. This can include regulatory, regional, human rights, privacy and gender impact assessments.[296] Generally, impact assessments precede key decision points, such as Cabinet deliberations. Some, including Australian Government impact analyses and human rights compatibility statements, may be published to ensure contestability and transparency.[297]

Evidence shows that with the right incentives and support structures, impact assessments can lead to improved policies, greater participation and transparency and improved long-term knowledge and learning.[298]

But while impact assessments are commonly used internationally and across policy domains, they continue to be underused for considering the impact of policies and services on the lives of people with disability.

In Australia, we are not aware of disability impact assessment occurring on a regular basis or being required for key policy decisions. Other processes, such as more general impact assessments and human rights compliance checks may capture some impacts on people with disability. While useful, we believe generalised assessments can miss the specific impact on people with disability.

> *"Disability inclusion has to be at the start – not at the end. Disability needs to be a core design principle for mainstream services, not something that gets considered at the end as a checkbox routine" – Person with disability* [299]

Compliance can be a key barrier to success for these processes.[300] There is a risk that any additional impact assessment process simply becomes an additional check box exercise, to be completed without careful consideration and therefore have limited influence. There is also the argument that impact assessments increase regulatory burden, or 'red tape', without providing additional benefit.

This represents a risk that should be addressed in the design of any impact assessment. Just as impact assessment is meant to mitigate the risk of bad policy outcomes, good impact assessment should lead by example and ensure design generates the best outcomes, including the management of non-compliance risks. While it of course increases the cost of making policy, it should also increase its rigour, and costs borne by policy makers are likely to be much smaller than the costs borne by people subject to suboptimal policy.

The introduction of high-quality disability impact assessments will promote the design and delivery of more inclusive and accessible services for people with disability and improve social and economic participation. This will not just benefit people with disability. It will benefit all citizens.

We acknowledge that the Disability Royal Commission has also recommend the introduction of Disability Impact Assessments by recommending that assessments are imposed on Commonwealth entities under the new proposed Disability Rights Act.[301]

3.1.7. Stronger action is required to tackle discrimination and create more inclusive and accessible communities

Stronger inclusion and accessibility requirements across governments are needed to reduce discrimination and uphold the human rights of people with disability, outlined in the UNCRPD and DDA.

Governments should significantly increase inclusion and accessibility, including through legislation, disability action plans, and service standards. The needs of people with disability should also be more genuinely considered as a part of government policy making processes.

We believe the following steps are required to make this happen:

- Review current Australian Government and state and territory disability discrimination inclusion and accessibility related legislation (including the DDA), with a view to identify opportunities to improve and harmonise legislation and practices. This includes considering in the review of the DDA, or broader updates to legislation based on Disability Royal Commission

recommendations, whether the DDA is the most appropriate mechanism and has adequate power to provide for measurable and enforceable mainstream services standards.

- Review the effectiveness and appropriateness of DAPs across jurisdictions, with consideration of a standardised format or approach.
- Develop guidance and resources for governments and other organisations on legislative obligations and best practice in inclusion and accessibility.
- Develop a mechanism or mechanisms to publicly communicate mainstream service standards performance, including whether a service is delivering at a higher quality than the minimum standard, such as a star rating system. This should be done in an accessible way that is easy to find and understand and supports people with disability. It could be trialled in priority mainstream services, such as school education, where it would build on the Disability Standards for Education. The trialling of a mechanism for Disability Standards for Education should have regard for the Early Childhood TAP, under ADS.
- Incorporate Disability Impact Assessments into new policy proposal assessment processes across all governments. As a first step, the Australian Government should commence an assessment pilot, building on existing legal, regional, and gender impact assessment processes with the intent to expand their use across all jurisdictions.

These reforms will be complemented by other actions across the Review, including:

- A dedicated initiative for the delivery of mainstream and community capacity building and planning supports (see Action 1.3). This program should be focused on supporting mainstream services and communities to be more inclusive and accessible for people with disability and the delivery of services that are appropriate to the needs of people with disability.
- A new navigation function for people accessing the scheme (see Action 4.1), that will ensure all people with disability receive navigation supports to connect with mainstream services, community supports, foundational supports, the NDIS and participate in their community.
- A new Disability Intergovernmental Agreement (IGA) to underpin delivery of a comprehensive and unified disability support ecosystem (see Action 20.1). The IGA should build on the foundation of the ADS and confirm the commitment of all governments to the UNCRPD. It should include measurable commitments and targets for improving the accessibility and inclusivity of mainstream services and the range and level of foundational supports.

3.1.8. Action & Implementation Details

Action 2.1: The Attorney General's Department, with the Department of Social Services and the states and territories, should develop a unified and contemporary approach to disability rights, discrimination and inclusion legislation.

This should improve and harmonise legislation including the Australian Government's *Disability Discrimination Act 1992* (DDA) and state and territory legislation. It should also consider the Disability Rights Act proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This should include assessing the scope, effectiveness and appropriateness of current Disability Standards under the DDA. It should also assess the effectiveness of disability action plans across jurisdictions in creating more inclusive and accessible mainstream services and communities for people with disability, and identify opportunities for nationally consistent reporting requirements, approaches and obligations. Reforms to disability rights, discrimination and inclusion legislation should have regard to Federation Funding Agreements and practical clauses to promote inclusion and accessibility (see Action 20.2).

Implementation detail:

The Australian Government, with states and territories and local governments, should:

* Review current Australian Government and state and territory disability discrimination inclusion and accessibility related legislation (including the DDA), with a view to identify opportunities to improve and harmonise legislation and practices. This should include considering whether the DDA is the most appropriate mechanism and has adequate power to provide for measurable and enforceable mainstream service standards.
* Review the effectiveness and appropriateness of Disability Action Plans and Disability Inclusion and Access Plans across jurisdictions. This should include exploring opportunities to improve and streamline reporting requirements and obligations across jurisdictions (including categories, timeframes and mandatory thresholds), and consider oversight mechanisms for reviewing and overseeing action plans.
* Develop guidance and resources for Australian, state, territory and local governments on legislative obligations and best practice in inclusion and accessibility.
* Consider bringing together the above actions as part of a Targeted Action Plan under Australia's Disability Strategy. This would ensure governments bring an intensive and coordinated focus on actions, people with disability are involved in the implementation of actions and there is clear accountability for progress and outcomes.

Action 2.2: All Australian governments should improve the recognition and responsiveness of government services to culturally and linguistically diverse concepts of disability and care by investing in targeted research, education material and capability building for government organisations and staff, professionals and providers who deliver government services.

Inclusive and accessible government funded services require increased knowledge on what disability and care look like in a variety of cultural contexts. Priority should be given to research and capability building initiatives that improve understanding across government services of how culturally-specific beliefs, relationships and familial obligations influence needs, help-seeking behaviours and experiences of government services. This should be supported by investments in community-led, culturally appropriate communication products that promote increased understanding of government services and supports in culturally and linguistically diverse communities. This should be underpinned by efforts to embed a highly skilled, person-centred, disability aware culture across all disability agencies and governments (see Recommendation 22).

Implementation detail:

- The Department of Social Services (DSS) and the National Disability Insurance Agency (NDIA) should invest in staffing the NDIA with people with lived experience of disability from culturally and linguistically diverse backgrounds.
- DSS should provide funding under the National Disability Research Partnership to prioritise research in partnership with relevant community groups (place-based, cultural, linguistically or racially diverse) improves visibility and understandings of:
  - How disability and care are conceptualised in a variety of cultural contexts
  - How cultural conceptions of disability impacts accessibility of the scheme, disability-specific service delivery and interactions with governments, institutions and systems
  - How intersectional discrimination impacts outcomes for culturally and linguistically diverse people with disability
- The NDIA should prioritise a joint review of all publicly available information, led by a culturally and linguistically diverse disability advocacy organisations for culturally insensitive content. This review should inform the contents of the forthcoming NDIA Culturally and Linguistically Diverse Strategy (currently under development), prioritising immediate remedy of any inappropriate content and future development of culturally appropriate resources for a variety of culturally and linguistically diverse communities.
- The NDIA and the DSS should partner with culturally and linguistically diverse communities to strengthen the culturally responsive nature of the disability ecosystem. This should include:

- Embedding the development of culturally relevant easy read guidance on participant information as a standard practice

- Tailored information on the legal governance and operations of the NDIA, scheme and foundational disability supports

- Funding to develop training resources to build the capability of disability service workers to engage effectively with cultural and linguistically diverse people with disability and their communities

- Funding to develop educational content for these communities to improve self-advocacy and understandings of exploitation.

Action 2.3: The Department of Social Services with relevant agencies should develop and trial a mechanism to publicly communicate the performance of current Disability Standards under the *Disability Discrimination Act 1992*.

This mechanism should be easy to find and understand and allow people to know whether a service is delivering at a higher quality than the minimum standard, such as through a star rating system. The mechanism should be trialled to highlight performance of mainstream providers against current Disability Standards, for example the Disability Standards for Education. These standards could be included in the Disability Outcomes Framework (see Action 23.1) and reported to National Cabinet by the proposed Disability Outcomes Council (see Action 20.5). This approach should have regard to the findings from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Action 2.4: All Australian governments should incorporate Disability Impact Assessments into new policy proposal assessment processes.

This should ensure adequate consideration of the impact of a new policy on people with disability. This should have regard to the new Disability Rights Act proposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and all state and territory disability rights and inclusion legislation.

Implementation detail:

The Australian Government should commence a pilot for the use of Disability Impact Assessments, building on the existing legal, regional, and gender impact assessment processes with the intent to expand their use across all jurisdictions. As part of the assessment the policy, program or service will need to state how it will:

- Ensure accessibility
- Promote universal design
- Reduce, remove and prevent barriers to inclusion
- Improve disability inclusion
- Align with the United Nations Convention on the Rights of Persons with Disabilities.

The following elements are key to successful implementation:

- Conduct assessments when developing or reviewing any policy, program or service that has a significant impact on the public, and would be considered by relevant Ministers before proceeding
- Develop supporting tools and training to build the capability and knowledge of public service employees
- Assessments are reviewed regularly by a responsible agency to monitor the progress of policy and service delivery proposals and inclusion/accessibility implications for people with disability
- Monitoring of progress should be included in the Disability Outcomes Framework (see Action 23.1) and reported to National Cabinet by the proposed Disability Outcomes Council (see Action 20.5).

3.2.   Connections between the NDIS and mainstream and community services are complex and remain difficult for people with disability to navigate

The introduction of the NDIS and its interface with many mainstream services, such as health and education, has made navigating multiple systems more difficult. Many of the issues raised consistently by people with disability stem from the failure of government agencies to agree on shared responsibilities and working arrangements under the current Applied Principles and Tables of Support to Determine Responsibilities of the NDIS and other Service Systems (APTOS). There is also a discussion of APTOS in Chapter 6 related to the role of governments' accountability for system responsibilities, but here the focus prioritises the implications for people with disability, their families and carers.

Clear responsibilities and effective coordination between agencies are critical for all people with disability. Mainstream services often have their own eligibility criteria and access requirements, which can be inconsistent and contradictory. In some cases, access to one support can preclude access to another complementary or necessary support, such as access to assistive technology, supports for children with developmental delay, or some supports provided in educational settings.[302] Deficiencies in the structure of APTOS are then compounded by funding arrangements

that, while intended to be citizen focused, instead reinforce siloed approaches and lead to debates about which service system should pay.

Without sufficient planning and integration, people with disability can experience not only complexity and inconvenience, but also negative health outcomes and risks to safety and wellbeing.

3.2.1. The APTOS was intended to determine responsibilities of the NDIS and mainstream services systems and ensure a coordinated approach to supporting people with disability

The APTOS was agreed by the Council of Australian Governments (COAG) in April 2013, and was updated in November 2015 to account for the early experiences of the NDIS trials. While the APTOS acknowledge that the agreed principles and related tables of support may need to change from time to time, no review or revision of the APTOS has taken place since 2015.

Over time as service systems have learnt about the NDIS and its role, a complex set of interactions have developed between the NDIA and other service systems. At the heart of these confusing and disempowering interactions, has been ambiguity in the design of APTOS, prioritisation of 'who pays' considerations and the fact the NDIS is a needs-based, uncapped system interfacing with rationed service systems.

This has meant the NDIA has faced significant challenges in balancing being responsive to the needs of participants with its responsibility to ensure the NDIS is sustainable. Without clarity in APTOS, the NDIS Act or its Rules, the NDIA has developed Operating Guidelines to determine its approach and guide the decisions of its staff acting as delegates of the Chief Executive Officer.

The APTOS sets out guiding principles to determine the roles and responsibilities of the NDIS and other service systems for funding and delivery of services, across 11 different mainstream interfaces. It is the primary document that the NDIA and other service systems refer to in their dealings with each other for coordination, navigation, and operational decisions.

The APTOS is supported by the NDIS Rules, which outline how the NDIA should determine whether supports are most appropriately funded through the NDIS. In implementing the decision as to whether a support is Reasonable and Necessary (and therefore funded through the NDIS), the NDIA uses its own Operational Guidelines. These guidelines are based on the NDIS Act and the NDIS (Supports for Participants) Rules 2013 and consider whether:

- It is more appropriate to fund and/or provide a support through means outside of the NDIS, and if so, that people with disability are assisted to coordinate these supports.
- The support represents value for money and is effective and beneficial.
- There is an impact to the financial sustainability of the NDIS by providing the support (NDIS Rules 2.5).
- The support helps the participant's participation and that they can pursue their goals and aspirations (section 34 and 2.3 of the NDIS Rules).

While the APTOS is replicated in legislation it is effectively subordinate to both the NDIS (Supports for Participants) Rules 2013 and the NDIS Act, as any of the considerations detailed in the above four points can override the roles and responsibilities stipulated in the APTOS. This is in line with the principles of the scheme as enshrined in both the legislation and APTOS, namely that the intention of the NDIS is not to replace the supports provided by other service systems and the broader community.

Figure 14: Diagram of APTOS standing in NDIS legislative framework
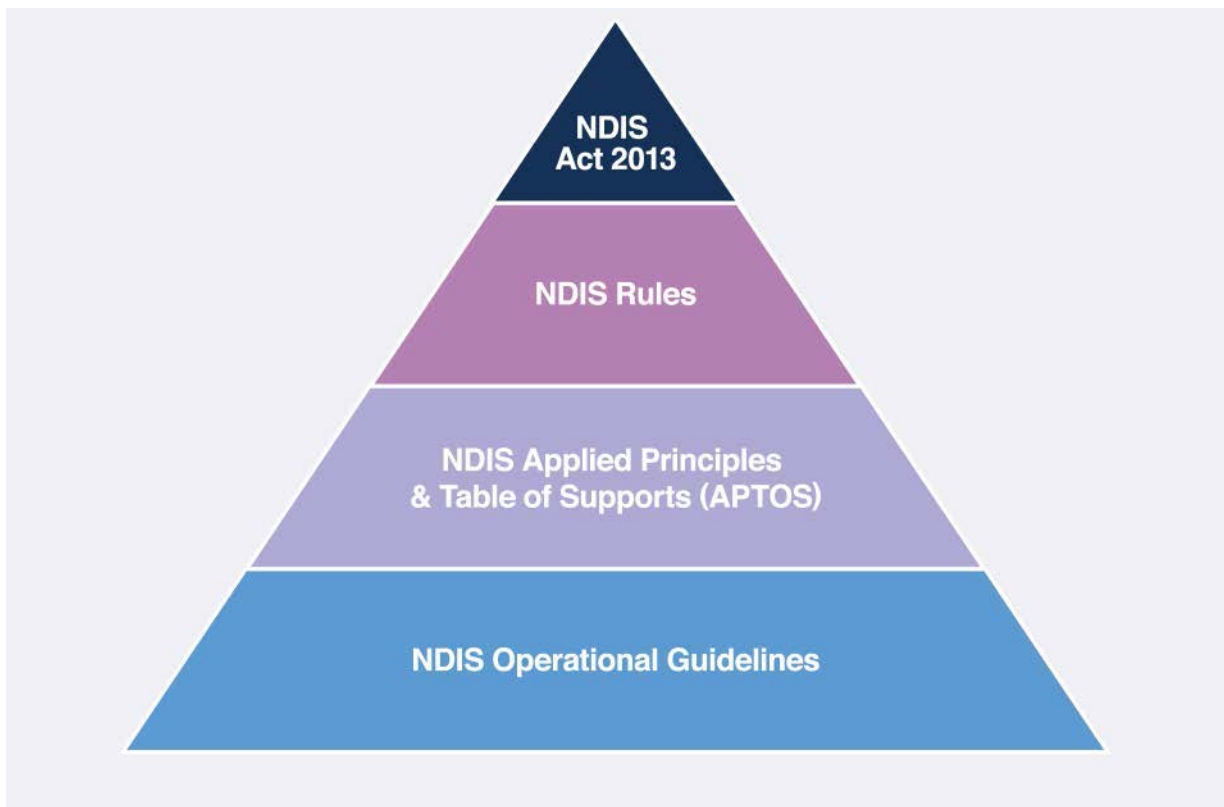
3.2.2. The APTOS has not translated into coordinated and consistent supports across systems

We have heard from key stakeholders that the six general principles underpinning APTOS are largely appropriate. These principles account for the right of access to services, personalised supports, along with the need for clear funding and delivery responsibilities, a nationally consistent approach to NDIS supports, efficiency, and a seamless and integrated planning and support coordination process.

However, the principles outlined in APTOS have not translated into consistent collaboration on the ground. The underlying structure of APTOS may be part of the problem - it assumes people with disability will be supported by the NDIS or another system, and that there are no gaps between the NDIS and other systems. In reality, many people with disability need support from both systems. This leaves people with disability confused about how and where to find and use supports, and in some cases with no access to support at all.

"... the APTOS have reinforced program boundaries and the one-dimensional, transactional approach of the old disability systems. In doing this, the APTOS have made it more difficult for people using the NDIS concurrently with other programs to get the 'joined up' services they need..... Rather than a level playing field of program responsibilities, their existence has entrenched the historical divide between programs and ensured program interactions focus on who pays, rather than the needs of the person with disability requiring their concurrent support." – Young People in Nursing Homes National Alliance [303]

"Currently, all three tiers of government do not cooperate or collaborate in order to achieve the best outcome for an individual. There is a push and pull between departments with everyone protecting their funding." – Autism Advisory and Support Service [304]

Through submissions and other detailed feedback from people with disability, families and carers, disability sector organisations, governments and other key stakeholders, we have identified several key themes that have limited the success of APTOS.

- **Unclear boundaries and operational guidance.** The APTOS can be complex and difficult to understand and interpret. Current boundaries and operational guidance do not provide adequate detail on responsibilities for who supplies what at the operational level. There is a lack of clarity on the distinction between disability-related supports and other supports (such as justice, child protection and health).

- **Poor information sharing and collaboration.** The APTOS incentivises binary and siloed approaches across support systems, which have led to a lack of effective coordination, information sharing and monitoring approaches. There is a lack of granular data and information on mainstream services as part of NDIS participant plans, as well as data and information gaps and inconsistencies. There are limited training and capability building activities to support the application of shared responsibility across support systems.

- **Challenges in applying APTOS across multiple interfaces.** People with disability, in particular people with complex support needs, experience difficulties in navigating and accessing support across multiple systems (such as education, health, child protection and justice). This can lead to delays in funding and support when moving from one service to another. There is a lack of consistency and coordination between government agencies, which can lead to disagreement of responsibilities between service systems. There is insufficient resourcing at the NDIA and other agencies to support the interaction between the NDIS and all mainstream service systems.

- **The perverse incentive to cost shift.** The NDIA and other service systems are too firmly focused on who should pay for what rather than participants or outcomes. There are different incentives between the NDIS (an uncapped system) and mainstream services (most of which are capped) which can lead to cost shifting. This is exacerbated by the fact the Australian Government is paying for all marginal NDIS costs, while in most other cases, with aged care

being a notable exception, the marginal costs are either shared between the Australian Government and states and territories or must be met by states and territories alone.

- **A lack of accountability and oversight.** There is insufficient weight behind APTOS and Disability Reform Minister Council decisions, which are not legally binding, and only serve as recommendations on NDIS policy matters under the NDIS Act. The NDIS (Supports for Participants) Rules do not provide adequate legislative guidance for NDIA decision makers with respect to what is reasonable and necessary. The effectiveness of the Administrative Appeals Tribunal (AAT) as an oversight mechanism for the APTOS has not been supported in practice, instead leading to scope increases of the NDIS without governments changing the legislation or rules to give legal standing to the APTOS approach. There isn't a robust *systemic* mechanism to hold the NDIS and other service systems accountable for funding and supports. This leads to endless *individual* arguments and appeal processes which are exhausting and dehumanising and leave people with complex support needs falling through the cracks.

Specifically, we have heard that the interface between the NDIS and palliative care can be difficult to navigate and can result in poor outcomes for people. When people are diagnosed with life threatening conditions and with very short life expectancies there is complexity as to whether support needs are best met by the NDIS or the palliative care and health system. While NDIS Rules clearly list palliative care as a health system responsibility, in practice what is palliative care and what is a disability support can be unclear or not sufficiently available, as participants may require palliative care, in addition to the functional supports to meet their lifetime disability support needs.

> *"There is growing confusion among disability and health service providers, consumers, and carers about which services and systems are responsible for the provision of supports (i.e NDIS, mainstream health services, disability supports outside of the NDIS, and aged care services) for people with a range of life-limiting illnesses. This lack of clarity may be compounded by inconsistency in NDIS assessors' decisions about initial eligibility to participate in the scheme, and inconsistency in NDIS plan managers' interpretation of participants' eligibility for different supports if they are diagnosed with a life-limiting condition." - Palliative Care Australia* [305]

This can lead to distressing experiences for people with significant impairments who need support, as well as for their families and caregivers.[306] It can also lead to longer than needed hospital stays. This interface should be considered as a critical priority area when reviewing arrangements for interactions between the NDIS and other service systems, noting issues exist across multiple interfaces. Clearer definitions of respective service system responsibilities and specific guidance on working arrangements should be developed to clarify these arrangements.

3.2.3. Unclear responsibilities and a lack of coordination have made it difficult for people with disability to find and access supports

Like the rest of the Australian community, people with disability rely on multiple service systems. However, situations are often more complex for people with disability. For example, an NDIS

participant with complex needs might rely on disability supports to access mainstream and community activities.

Collaboration between the NDIA and mainstream services is fundamental to achieving good outcomes for people with disability through the effective operation of the NDIS. A recurring theme in evidence provided to us is that collaboration between service systems can be inadequate, characterised by a lack of clear strategy and governance across services. Many participants and their families feel more time is spent arguing about who is responsible for what (and which service system should pay) rather than working together to get the best outcomes for participants.[307]

Without sufficient planning and coordination, people with disability, families and carers are left confused about how and where to find and use supports, and in some cases with no access to support at all. Submissions to the NDIS Review and previous NDIS related inquiries have consistently described key issues arising from unclear responsibilities and a lack of integration across support systems. These issues include:

- Complex and inconsistent eligibility criteria

    - People with disability, families and carers are often required to gather extensive documentation and undergo numerous assessments to determine eligibility for different NDIS and non-NDIS programs and supports.[308]

    - People with disability, families and carers face a significant administrative burden across systems and must regularly deal with lengthy wait times following an application or assessment process.[309]

    - In some cases access to one support can preclude access to another complementary or necessary support, such as access to assistive technology, supports for children with developmental delay, or some supports provided in educational setting.

    - In other cases, access to one support can be conditional on access to another support reinforcing 'winners' and 'losers', for example in education in some jurisdictions.

    - The difficulties in navigating support system means often only the most articulate and well-resourced can find their way through. This can lead to people receiving delayed or no support at all. In some cases it can have dire consequences such as homelessness and reoffending.[310]

        "By default, NDIA inequitably favours the most capable [including those with advocates] and pays insufficient attention to the most vulnerable." – Carer [311]

        "[...] All systems should provide wraparound care rather than disjointed services or denying services altogether." – Australian Association of Psychologists [312]

- Misalignment of supports and participant goals

    - Poorly coordinated supports can lead to siloed service delivery that fails to consider the impacts of inadequate support from other systems. For some participants this has led to

suboptimal progress, wasted resources, and conflicting guidance or mixed messaging. A specific example of this misalignment are the conflicting definitions used between the aged care sector and the NDIS, identified by a provider which operates in both systems:

"Positive Behaviour Support vs behaviour management, and differing definitions of what constitutes Restrictive Practice being two key examples in this space which impact on service providers ability to provide consistent, high-quality support and care." – Wintringham [313]

- For participants that have needs that intersect with multiple service systems or require extensive therapeutic supports, this can lead to their needs being segmented into parts (for example behavioural versus developmental versus medical), which are either only partially addressed or left to one provider to try and coordinate and implement with other providers.[314]

"The National Disability Insurance Scheme has disrupted integrated service provision. The NDIS creates an environment in which disjointed services are the norm: one professional does not communicate with another." – Royal Children's Hospital [315]

- A reactive approach to supporting people with disability

  - A reactive approach has led to a failure to properly sequence or provide, or appropriately respond to trauma and disadvantage.[316] This can result in a participant falling into crisis.

  - People with disability face barriers accessing support in times of crisis, which can put a person's health and wellbeing at risk.[317] This can be seen in notifiable incidents and actions in the justice, child protection, school education and mental health systems.[318]

    "There are schools who give rolling suspensions to students with complex needs. They say it is to look at options and resources. In the meantime, the student and family are disadvantaged. This process is a vicious circle as many students do not have the capacity to understand why they cannot go to school and for those who enjoy home better, they will then duplicate the behaviours to stay at home." – Autism Advisory and Support Service[319]

- Insufficient training and knowledge for NDIA and mainstream service staff

  - A lack of training for NDIA and mainstream staff can diminish support quality and leave participants disconnected from the right supports

  - Some NDIA and mainstream service staff lack the knowledge and capability of other support systems and/or do not recognise the expertise of others. This can lead to participants being directed to the wrong provider of a service, or even discouraged from using an appropriate provider.[320] This issue is particularly acute for people with complex needs and in areas where support options are limited.[321] [322]

- **Lack of information sharing and risk identification**

  - There is a lack of appropriate and efficient information sharing and risk identification processes between the NDIS and mainstream services. This extends to a lack of integration in incident reporting.323

  - Decision making across service systems can also be contradictory and inefficient due to cases not being managed consistently by the same staff.324 This can lead to people with disability, families and carers struggling to find the right channels to lodge complaints.[325]

    "Integration and communication between services seems to be non-existent in Broome even though a number or organisations and schools seemed to say the same thing. There is no coordination or information sharing between services and as a result some participants are given different information." – First Peoples Disability Network[326]

These issues have led to many NDIS participants being under-supported and unable to access the services they need. Participants have to frequently explain their situation and needs to different providers and agencies. The result is a disjointed, inefficient and stressful experience where participants either have had to talk to numerous experts and providers to access coordinated supports or are unable to receive coordinated supports.[327]

"Not having a consistent contact point means that I feel like I have to repeat my story on multiple occasions, and that I am just a random 'client', not a family and a human with a story, cause and knowledge that I bring." – Carer [328]

3.2.4. Clear responsibilities and effective coordination between agencies are critical for people with disability finding and accessing appropriate supports across systems

The framework which governs the relationship between the NDIS and other service systems - the APTOS - has failed. It is based on the idea that there is a hard line between the NDIS and other systems. And despite its intent, it has led to seemingly endless arguments about who does what and who pays for it.

We recommend the APTOS be replaced with a multilateral schedule (see Action 2.6) under the new Disability Intergovernmental Agreement (IGA) (see Action 20.1). The schedule should clarify the core principles for how the NDIS and other services systems will operate, provide detail on shared responsibilities and update single system responsibilities. Memoranda of understanding (MoUs) between the NDIA, the new National Disability Supports Quality and Safeguards Commission, and mainstream services should be developed to agree detailed working arrangements, including safeguarding arrangements between and across systems, guided by the principle that systems must work together to support all people with disability. This is critical in all areas but particularly for health, justice and school education.

Bilateral agreements would be required between the Australian Government and state and territory governments to agree to implement MoUs for specific interfaces, which would then flow through to NDIA Operational Guidance. The Operational Guidance should be publicly available and be

developed with the higher-order instruments used as source materials. This framework would operate under the principle of embodying responsibilities multilaterally where we can, bilaterally where we must.

The new multilateral schedule arrangements must ensure that there is an active feedback loop between policy, legislation, operational guidelines and merits review. Where the AAT or other courts make findings that shift the boundaries between the NDIS and other service systems, governments through Disability Reform Ministerial Council (DRMC) need to assess whether they accept this change and update the multilateral schedule, MoUs and operational guidance or introduce new legislation or rules.

Figure 15: Details the mechanism by which these instruments would operate
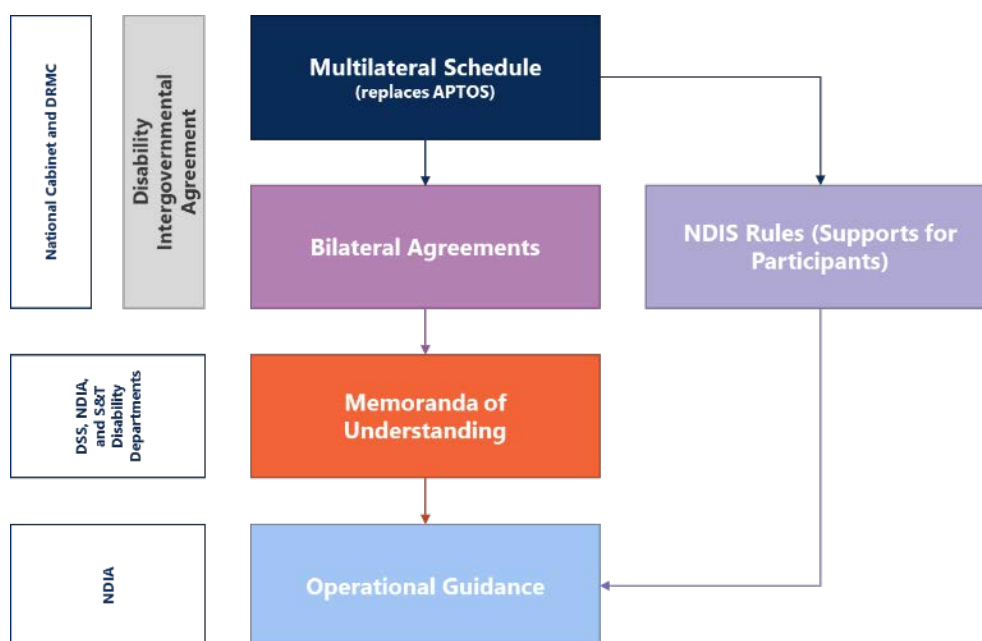
To support the design of MoUs between the NDIA and mainstream services we recommend consideration of the current MoU for children and young people with disability in Voluntary Out of Home Care (VOOHC). Currently this the only major instrument outside of the NDIS Act, Rules, and APTOS used to promote collaboration and joint responsibility between service systems.

Case study 3 below provides more information on how this MoU has worked in practice in the context of VOOHC arrangements where a parent or guardian arranges for out of home disability care for a child, as opposed to statutory out of home care resulting from a protective concern. Arrangements in each state and territory for both VOOHC and the interface with the broader child protection system are complex. While there is a comprehensive agreement between governments and the NDIA in place for VOOHC, we have heard that there are still significant challenges across the child protection and NDIS interfaces.[329] Notwithstanding the positive evaluation received by Ministers on the operation of the VOOHC MoU in 2021, this feedback highlights the need for further work to ensure these critical interfaces operate as effectively as needed.

Case Study 3: Voluntary Out of Home Care – Memorandum of Understanding

In 2019, the NDIA, DSS, and state and territory governments (represented by their child protection departments) entered into Memoranda of Understanding (MoU) in relation to the arrangements for the administration of children and young people with disability requiring accommodation outside the family home - also known as Voluntary Out of Home Care (VOOHC).

This was agreed to by the Disability Reform Council in June 2019, following long standing issues on how the NDIS and other service systems could better support children and young people with complex disability support needs. These MoU were implemented bilaterally through model agreements between the NDIA, DSS and each individual state and territory.

To support shared responsibility parties have enshrined the following in the MoU:

- Acknowledgement of the fact that disability supports in the family home help families to sustain care arrangements and help to facilitate access to mainstream supports

- Acknowledgement of the importance of stable and supported arrangements for children and young people in VOOHC, and their connection to family and culture

- Joint responsibility for providing early intervention supports to families to prevent VOOHC or statutory care placements

- An integrated response at the local level, including collective decision-making processes and reviews, and the development of standard parental agreements.

- A clarification of roles and responsibilities for families in a VOOHC arrangement, including the use of family capacity-building through NDIS supports

- A clear delineation of who is responsible for which supports

- Specified funding parameters for certain supports (such as the cost of accommodation).

- Joint development of risk identification characteristics, indicators, and oversight to better identify VOOHC demand requirements in the future

- Information sharing protocols detailing when and how information can be shared and used

- The commitment to work collaboratively through a senior officials group to resolve operational and implementation issues related to the MoU.

A 2021 review of the VOOHC MoU found that the arrangements were working as intended, but that more work needed to be done on earlier identification of cohorts, refining joint decision making, targeting of supports, and data collection and information sharing. We have heard that the latter has been a persistent issue with respect to state and territory child protection systems experiencing problems accessing the requisite information from NDIS Portal in order to address VOOHC service needs.

Action 2.6: National Cabinet should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities

This multilateral agreement should clarify distinct system responsibilities and shared responsibilities (who does what and how) where a participant needs integrated planning, funding and supports. Shared accountability, including monitoring of outcomes and key performance indicators, for operationalising interface-specific arrangements, should be set out in bilateral schedules and Memoranda of Understanding (MoU). This framework should operate under the principle of setting responsibilities multilaterally wherever possible and bilaterally in other cases. Agreed responsibilities should be incorporated into the NDIS Participant Support Rules and other NDIS Rules governing reasonable and necessary supports, including expectations for shared planning and information sharing. The multi-lateral schedule should set parameters for sharing costs for complex case resolution to ensure meeting the needs of people with disability are prioritised rather than who pays for what.

Implementation detail:

The Department of Social Services (DSS) with states and territories should develop a multilateral schedule to a new Disability Intergovernmental Agreement (see Action 20.1). The multilateral schedule should:

- Strengthen existing APTOS principles and detail shared responsibilities for the provision of concurrent supports. This will include accountability for meeting regulatory obligations in shared delivery situations (such as joint clinical governance)
- Clarify existing responsibilities that are disputed or ambiguous and add new responsibilities where gaps exist
- Detail shared planning and funding arrangements for concurrent supports underpinned where required by interface specific MoUs
- Redraft responsibilities and ways of working for the mental health interface to reflect a new dedicated pathway and the need to ensure concurrent clinical and disability supports for all participants (see Recommendation 7)
- Facilitate significant updates for key interface areas including justice (including forensic issues), health (including palliative care), early childhood development and school education
- Be supported by a mechanism to support the timely resolution of system and individual-level issues, such as Hospital Liaison Officers and Justice Liaison Officers (see Action 2.7)

- Include the use of Key Performance Indicators based on timeliness of response, cross-system collaboration, service continuity, client outcomes and satisfaction
- Specify the feedback loop process where future changes and updates agreed by Disability Reform Ministerial Council are reflected in the multilateral schedule, relevant MoUs and updated operational guidance. This includes reflecting agreed changes and updates in the Participant Rules.

The National Disability Insurance Agency (NDIA), with support from DSS, should develop MoUs with states and territories for specific interface areas specified in bilateral agreements. Each MoU should:

- Outline detailed operational roles and responsibilities, and how principles will support the coordination and management of shared responsibilities
- Detail approaches for referrals, coordination and complex case management that are appropriate to the interface
- Detail how supports will be coordinated and delivered within the complex mainstream setting and the NDIS, where appropriate. This should have regard for priority work program to improve coordination between complex mainstream settings and the NDIS (see Action 2.7), including the best practice case management approach and NDIS Complex Support Needs Pathway
- Facilitate information and data sharing between Australian Government and state and territory agencies
- Be publicly available and accessible for people with disability, the disability sector, governments and the community.

The NDIA should update and republish NDIS operational guidance and NDIS Participant Support Rules, to reflect the new multilateral schedule and interface MoUs. Updates to NDIS Participant Support Rules should have regard to broader *NDIS Act 2013* reforms (see Action 21.2).

3.3. There is poor coordination between complex mainstream settings and the NDIS, resulting in worse health, social, and economic outcomes for people with disability

3.3.1. People with disability who interact with complex mainstream settings often require additional, coordinated and specialist supports

There is a combination of personal and situational factors that can lead to complexity for a person with disability in a mainstream setting (such as a hospital, prison, mental health facility or child protection). Complex mainstream settings are typically characterised by:

- **Complex support needs** – People with disability in these settings often have more complex support needs, compared to the broader Australian population. These may be driven by personal, social and environmental characteristics, as set out in the International Classification of Functioning, Disability and Health (ICF), such as chronic health needs, multi-generational disability and disadvantage, co-morbidity, trauma and abuse history, episodic needs, disengagement from supports, behavioural issues, domestic violence, socioeconomic disadvantage, and drug and alcohol use.[330]

- **Worse impact on people with disability** – There is a disproportionate impact on people with disability when they interact with these settings, relative to the broader Australian population. People with disability are overrepresented in the justice and child protection systems, and interact more with hospital and mental health services than people without disability.[331] This overrepresentation is particularly acute for people with cognitive and psychosocial disabilities. The effects can be grave as people with disability experience worse health, social, and economic outcomes when supports are inadequate.

- **Ambiguous responsibilities** – There is a lack of clarity regarding what is a disability and a non-disability support and who is responsible for delivering it within these settings. Quite often a support that addresses a disability need also addresses non-disability support needs, and vice versa. Ambiguous responsibilities result in service gaps, as neither service system considers the support to be their responsibility and inefficiencies, when supports are duplicated by the NDIS and mainstream services.[332]

- **Crisis response** – Complex settings can either be consequences of or contributors to crises, with a service provider needing to step in to ensure the circumstances do not worsen for people with disability. However, the NDIS and mainstream services have inconsistently discharged their responsibilities in these settings. Some examples include interim accommodation in justice, respite and placement changes in child protection, and extended stays in hospital.

- **Involvement of multiple service systems** – Supports often need to be provided from multiple mainstream service providers in addition to the NDIS.[333] For example, a person with disability in the criminal justice system may need to interact with and receive supports from the health, mental health, housing, and employment systems. This requires a coordinated effort to ensure supports are provided.

- **More planning and coordination to transition from settings** – Planning and coordination of supports to assist people with disability to transition to life outside of the setting is more critical, involved, and resource intensive than for people without disability.[334] For example, after-care planning for young people leaving Out of Home Care (OOHC).

Governments have undertaken several responses to support people with disability interacting with complex mainstream settings, including:

- The NDIS Complex Support Needs Pathway (CSNP)
- Support coordination
- Specialist Disability Accommodation with complex support

- Behaviour support plans
- Specific roles to address the challenges in delivering and coordinating supports in hospitals (Health Liaison Officers) and prisons (Justice Liaison Officers)
- Mainstream service systems, which will sometimes have their own navigation services.

While a focus on hospitals and has led to some recent improvements, there has been limited progress in addressing issues across complex systems, particularly when participants transition from complex settings into the community.[335] This is due to ambiguity in responsibilities between the NDIS and mainstream services, poor planning and coordination. The absence of a dedicated NDIS case management approach and a lack of supply of key infrastructure, such as step-down facilities when people with disability leave hospitals and their long term community support needs are still not clear. [336]

Box 6: Examples of complex mainstream settings across the Justice, Child Protection and Health interface

Justice

The primary settings are correctional facilities such as: jails, pre-trial detention (for example, remand), youth justice facilities, and forensic facilities (for example, when a person with cognitive disability is found 'unfit to be tried' and is detained as a 'forensic patient'). There are also services and settings adjacent to these where preventative and transitional supports (including disability supports) are provided in the community and can include court-based diversion programs (for example cognitive impairment diversion programs), custodial supervision orders, and civil orders (for example Supervised Treatment Orders in Victoria).

Child protection

Child Protection settings can include home-based care (for example statutory and relative/kinship care), residential care, group homes, independent living, voluntary out of home care, respite, and crisis accommodation.[337] Services and settings adjacent to these include early intervention services (such as family preservation services), restoration and family supports and independent living supports for children and young people exiting OOHC.

Health

For the health interface, settings can include hospitals, private practices, palliative care, and some community settings like residential facilities, time-limited short-term rehabilitation services (for example From Hospital to Home, Safe and Supported at Home, etc.)

3.3.2. A lack of clarity on who is responsible for delivering supports within complex mainstream settings leads to people missing out

There are ongoing disagreements between the NDIA and mainstream service systems over who is responsible for the provision of supports when people with disability interact with multiple mainstream settings in complex ways. This can lead to people with disability receiving duplicative support or not receiving support at all. The key factors contributing to the current state include:

- **Disagreement over whether a support is disability or non-disability related** – This is evident in criminal justice, child protection and health systems when support needs can be related to disability, behaviour, trauma or health needs. Even when a person with disability is transitioning (or has transitioned) from a complex mainstream setting, it is difficult to distinguish between the specific needs being addressed. For example, a support worker assisting a participant that has been released from custody with daily needs may also be assisting with social skills which can reduce the risk of reoffending.

  "As the child protection departments are state funded and NDIS is commonwealth funded, they keep blaming each other and saying that each other is responsible for the cost. Newsflash - we don't care, we just need the help we need!" – Carer[338]

  "People leaving the criminal justice system should have their 'whole safeguarding' needs assessed and not disconnect the persons disability from other developmental needs or the 'harmful behaviour' that resulted in them being in the criminal justice system in the first place." – Community Living Options[339]

- **Challenges managing shared responsibility** – Supports such as family capacity building, early intervention and behavioural supports for children can be delivered by the NDIS or mainstream support systems. This can lead to a lack of clear responsibility. Similarly, capacity building supports can address both disability and criminal behavioural needs.[340]

  "If the consumer is consenting, there really needs to be more co-ordination with other involved services. I am often shut out of NDIS and have no idea if there is doubling up of services. This is vital for mental health consumers in particular." – Government organisation[341]

- **Inconsistent decision-making for concurrent supports** – We have heard of inconsistencies in the provision of disability-related health supports by the NDIA and Local Area Coordinators for diabetes, continence, wound care, nutrition, and dysphagia. The criteria for NDIS approval of various concurrent supports is unclear.[342]

  "NDIA reports are questioned by unqualified Local Area Coordinator's and upper management Planners. Many ... clients after paying for a continence assessment as requested by NDIS, are being advised by their planners and LACs that their plans are being cut in continence funding" – Continence Specialist Services[343]

- **Limited or inadequate support coordination and case management** – We have heard of multiple cases of participants in OOHC and the criminal justice system who have not received an adequate level of intense and expert support coordination and that some planners lack expertise or knowledge. This means case management style functions are taken on by staff and carers outside of what is funded.[344]

    > *"The role of a support coordinator as an intermediary, under the NDIS, has changed since the initial launch of the scheme. Despite the insistence that support coordination is not case management, the expectation of the NDIS has extended to include resolution of complex individual issues within a range of other systems, such as the justice and health. The complex nature of these intersecting areas does in practice require a case management approach, particularly when the situation is dire, and the participant has no family or informal support networks." –Provider[345]*

- **Challenges in organising and delivering supports** – Even where it is clear the NDIS should provide a disability-related support in a setting, delivery may not be feasible due to restrictive operational requirements, such as protocols and procedures that need to be adhered to in prisons and mental health facilities.[346] These requirements can discourage NDIS providers from even entering and delivering supports.

- **The current NDIS model of care is not fit for purpose for people with complex needs** – The NDIS pricing methodology does not adequately account for higher unit costs associated with complex clients. For example, there are no competencies required for providers and no evidence-based outcomes measurement framework. There is a lack of incentives for the supply of services for complex clients (stemming from issues around OHS, skills, staff retention and price signals). The 2018 Independent Pricing Review made two recommendations that the NDIA should define complex and allow for loading adjustments for complex participants.[347] These recommendations do not appear to have been implemented. We have heard that high quality providers face an invidious choice at times when providing supports to complex clients. They can continue providing support at a loss, which undermines their viability or relinquish the service knowing that any new provider is likely to cut essential supports or may not have the needed high skills.

    > *"The cost model fails to consider the additional costs beyond the support worker wage, to ensure quality, safe supports for vulnerable customers with complex support needs."*
    > *– Avivo[348]*

3.3.3. A lack of appropriate support in complex settings has negative impacts on people with disability, families and carers

A lack of appropriate support in complex mainstream settings has negative social and health impacts on people with disability, families and carers. The most significant of these impacts include:

- **Children with disability in vulnerable circumstances miss out on critical and timely support** – Some NDIS participants receive reduced disability-related support from the NDIS once they enter child protection or OOHC settings. This is supported by evidence from New South Wales (NSW) where NDIS plan utilisation is lower for children in OOHC compared to those not in OOHC and where some children have significant underspends and others have no expenditure against their plans.[349] Delays in support provision and lack of support can detrimentally impact children, leading to "developmental delays, decreased social skills and increased behavioural challenges."[350]

- **Limiting or breaching people's human rights** – For example, in forensic settings where disability supports are not being provided or not provided sufficiently, participants remain in custody due to decision makers' concerns over whether there may be a risk of self-harm or harm to others in the community.

- **Poor health outcomes** – A lack of appropriate support in hospital settings can have dire health consequences such as infection, the deterioration of health-related or disabling conditions and even death.[351] Where there is a lack of supports before, during, or after transitioning from hospital, there can be wide-ranging impacts that lead to unnecessary hospital admissions and delayed discharges. People with disability are often at risk of poorer life and health outcomes than others that interact with complex settings. The consequences of inadequate supports can lead to family violence, extended stays in hospital, and deterioration in health and wellbeing.[352]

  "Clients are having their funding cut for services such as catheter care and bowel care, which is impacting their ability to stay in their own homes. We have clients that have required to be hospitalised due to not having the funding to pay for the supports they need. These supports could be managed at home instead of clogging up an already struggling hospital system." – Provider[353]

  "But, it seems NDIS only care for clients when they are well and living at home. When she is ill, she needs more support, but that is off the table. It is known that people with complex disability and mental health needs have greater needs in unfamiliar situations in hospital - not less." – Carer[354]

- **Overrepresentation in the criminal justice system -** Failures to address support and coordinate needs contribute to the continued overrepresentation of people with disability in custodial and forensic settings. The Australian Institute of Health and Welfare (AIHW) found that 29 per cent of the Australian adult prison population in 2018 had a disability,[355] while 95 per cent of First Nations people who appear in court charged with criminal offences have an intellectual disability, a cognitive impairment or a mental illness.[356]

- **Homelessness and reoffending** People with disability in the criminal justice system (including forensic patients) suffer significantly higher levels of abuse, violence, neglect and cruel and unusual punishment.[357] Insufficient levels and coordination of support when people with disability transition from correctional settings leads to greater risk of homelessness and reoffending.[358] For example, young people with disability in NSW have been found to be more

likely to re-offend within two-years compared to those without disability.[359] The lack of and delays in support provision can lead to a cycle where support needs are only identified and escalated when people with complex disability needs re-enter custodial settings.

- **Impacts on the broader service ecosystem** – Inadequate support for people in complex settings can lead to cost impacts for the NDIS and other mainstream services. This can mean resources are not able to go to other critical services or negative spillover effects on adjacent services. The issue of delays in hospital discharge is a prominent example of this.

Box 7: Impacts of delays in hospital discharge

This occurs when participants who are in hospital inpatient care are medically cleared for discharge but have no safe and appropriate destination available or arranged outside of hospital.[360] As a result, patients remain in hospital until appropriate supports and facilities are identified and made available. The key impacts of these situations are:

- Participants are forced to remain in a hospital bed until a decision is made on their support needs or until supports become available. This is demeaning and impacts on health and wellbeing as participants are separated from familiar people and environments
- Fewer inpatient beds are available impacting on the wider health system through backlogs in admission from emergency departments, and longer wait times for ambulances and elective surgery
- Overall costs increase and are shifted inefficiently across different levels of government either through the health system, the NDIS, or the premature moving of a participant to other less appropriate service systems such as aged care.

We acknowledge the NDIA has undertaken reforms to support the safe and timely discharge of NDIS participants, including:

- A commitment to contacting every participant (or their authorised nominee or representative) within 4 days of being notified that they have been admitted to hospital
- An increase in the number of NDIA staff nationally who work directly with the health system, called Health Liaison Officers.

As at 31 December 2022, hospital discharge delays had reduced to 33 days from 160 days in early 2022.[361] However, challenges in relation to appropriate step-down facilities in some jurisdictions and locations remain. This will require ongoing shared endeavors between the health systems in each jurisdiction and the NDIA.

3.3.4. Reforms are urgently required to improve how supports are delivered and coordinated in complex mainstream settings.

We recommend the development of a priority work program that clarifies government responsibilities and improves the coordination between the NDIS and mainstream services. By doing so, this will ensure people with disability who interact with complex mainstream settings receive adequate and effective support.

Agree working arrangements through jurisdiction-specific Memoranda of Understanding

We have recommended development of a multilateral schedule to the new Disability Intergovernmental Agreement to replace the APTOS (see Action 2.6). The multilateral schedule should clarify distinct system responsibilities and articulate the shared responsibilities of the NDIS and other service systems. The schedule will articulate working arrangements at an interface-specific level – essentially who does what and how they should do it. This is particularly critical where participant needs require integrated planning, funding and concurrent support provision.

Consistent with this new schedule, jurisdiction-specific MoUs should be developed to step-out more detailed working arrangements at the interface between the NDIS and the child protection, justice, health and mental health systems.

Introduce case management

The NDIS currently funds specialist support coordination (level three) for participants whose situations are more complex and who need specialist support. The intent of specialist support coordination is to assist participants manage challenges in their support environment and ensure a consistent delivery of service.[362]

We have heard that current approaches to case management for participants, including specialist support coordination, who interact with complex mainstream settings have been insufficient and require reform.

We recommend the development of a best practice approach to case management for complex mainstream settings. The approach should:

- Define the vision and objectives, and outline key outcomes expected
- Detail how all governments will work together to ensure coordinated and effective case management approaches for people with disability in complex mainstream settings, including mechanisms for joint planning and funding
- Map and consider existing support coordination functions, including specialist support coordination, the roles of Health Liaison Officers and Justice Liaison Offices, and specific state and territory coordination and case management functions such as the NSW Government's former Integrated Service Response (ISR) and the Victorian Government's statutory complex coordination models
- Build on the improved working arrangements between the NDIA and hospital staff developed through the national operational plan for improved hospital discharge

- Establish communities of practice and consistent approaches to data collection across jurisdictions to create learning systems in these complex areas to drive improvements over time. This could then be linked the National Disability Data Asset and the proposed new research agenda (see Actions 23.3 and 23.4).

The best practice approach should be complementary to the proposed Specialist Navigator for participants with more complex support needs (see Action 4.2). This will be achieved by developing and implementing a complex case management responsibility framework which will clarify the roles and accountabilities of NDIA staff, mainstream service staff and specialist navigators. The approach should be available for those interacting with acute service systems and where complex situations or significant risks have been identified as part of the access or Needs Assessments. Then, Specialist Navigators should provide a higher level of support to participants when delivering Navigator functions to help respond to the participant's complex support needs, environmental complexity, or mitigate risk.

Case management in the mental health system should be operationalised through the establishment of an integrated complex care coordination approach with public mental health systems for participants with complex needs (see Action 7.3). The integrated complex care approach should be a co-funded and co-commissioned initiative between the NDIS and public mental health systems for participants with complex support needs and active mental health management issues. NDIS participants with a psychosocial disability should have access to Specialist Navigators who would provide a higher level of support to participants when delivering Navigator functions to help respond to the participant's complex support needs and ensure a recovery focus (see Recommendation 4).

3.3.5. Action & Implementation Details

Action 2.7: The Department of Social Services, working with other Commonwealth agencies, state and territory disability agencies and the National Disability Insurance Agency, should implement a priority work program to improve coordination between complex mainstream settings and the NDIS.

As a first step, the program should ensure Memoranda of Understanding are progressed immediately for the justice, hospitals, mental health and child protection interfaces in each jurisdiction. A best practice case management for complex settings approach should be developed and implemented. This should include assertive outreach to identify and support people with disability interacting with complex settings prior to them commencing NDIS access. The roles of Specialist Navigators, key mainstream agency workers and key National Disability Insurance Agency (NDIA) workers should be formalised as a panel of decision-makers to ensure system coordination to meet complex needs. Where necessary, this should include shared planning and shared funding. The roles of the Hospital Liaison Officers and the Justice Liaison Officers should be reviewed and clarified within the new case management

for complex settings arrangements. The NDIS Complex Support Needs Pathway should be reviewed and updated to reflect these new case management arrangements. This should build on the improved working arrangements between the NDIA and hospital staff developed through the National Operational Plan for improved hospital discharge.

Implementation detail:

The Department of Social Services (DSS) with the NDIA and state and territory portfolio agencies should develop a best practice case management approach. The approach should:

- Define the vision and objectives for best practice case management in complex mainstream settings
- Outline key outcomes expected from case management in complex mainstream settings
- Design and operationalise a case management model in complex mainstream settings
- Detail how all governments will work together to ensure coordinated and effective case management approaches for people with disability in complex mainstream settings, including mechanisms for joint planning and funding
- Map and consider existing navigation and case management functions, including specialist navigators, Health Liaison Officers and Justice Liaison Offices, the NSW Government's former Integrated Service Response (ISR) and the Victorian Government's statutory complex coordination models
- Develop agreed approaches to creating communities of practice and implementing enhanced and consistent data collection and research to drive improvements over time

3.4. Poor coordination across the First Nations and disability ecosystems is compounding the marginalisation of First Nations people with disability

3.4.1. The western concept of disability does not readily translate into First Nations ways of being, doing and seeing

Disability is a western concept that is informed by western cultural ideals and values of individualism, self and market capital which informs labels of "normal" and "disabled". The shared cultural ideas and values that underpin First Nations people in Australia are that of interdependence, relationality and wellness.[363]

> *"Aboriginal and Torres Strait Islander peoples' approach to health and wellbeing is holistic, placing equal emphasis on physical, social, emotional and cultural wellbeing, which are interconnected. Disability also needs to be understood through this holistic lens, which centres culture, community and Country." – Lowitja Institute[364]*

This foundational difference means that often when disability supports focus on the individual needs they do not fully reflect First Nations' values and needs, compromising social and emotional wellbeing, family relationships and cultural obligations. This results in supports that are not culturally inclusive or safe, as providers struggle to grasp how disability may be constituted through First Nations family groups, centring supports on the needs of individuals at the exclusion of impacted family groups, kin, extended networks and carers.[365]

The importance of social obligations, connections to kin and caregiving in First Nations communities should not be underestimated. Caregiving is an important dimension of First Nations cultural responsibilities, and inadequate support for carers can result in damaged cultural relationships, failure to uphold cultural responsibilities and bring shame on individuals and disruption to communities. First Nations people with disability also perform caregiving roles, therefore inadequate supports for carers is likely to adversely impact individuals with a disability.[366]

3.4.2. First Nations people with disability represent a unique intersectional cohort in Australian society

First Nations people experience disability at up to twice the rates of non-Indigenous Australians. High rates of community participation, low socio-economic status, compounding inequality, and a mismatch in the communication of what it means to be a person with disability create a unique mix of factors that influence the everyday lives of First Nations people with disability.[367]

The fundamental disconnect between western individualised concepts of disability and cultural models of collective care and inclusion informs communication barriers which reinforces a reluctance among First Nations people to identify with the non-Indigenous concept of disability. This impacts the quality of First Nations disability prevalence data. "Do you have a disability? Is a question that is culturally insensible for Indigenous peoples."[368]

Noting these limitations, current data indicate that anywhere from 24 per cent to 38 per cent of First Nations people are living with disability.[369] The National Aboriginal and Torres Strait Islander Health Survey 2018-19 indicates that First Nations people are 1.5 times as likely to be living with disability and 2.5 times as likely to be living with "severe or profound" disability.[370] While the 2018 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers estimated that First Nations people are 1.9 times as likely to be living with disability as non-Indigenous Australians.[371]

3.4.3. Inconsistent understandings of First Nations concepts of disability and care, ways of being and cultural obligations are undermining efforts to improve outcomes

Traditionally, Australian disability policy has focused on improving inclusion and participation of people with disability in Australian society. However, this participation has not been conceptualised in ways that are always meaningful to First Nations people and fail to recognise their lived realities.

"Certainly for our clients definitely feel that they are part of their community. I mean, they're certainly First Nations clients who are [integral] parts of their families, so for the most party

they don't actually even see their disability necessarily as a disability, yeah, The people that we seem to see are actually an [integral] part of our society." – Disability Advocacy Network Australia (DANA)[372]

First Nations people with disability are included in their communities in the same way as their peers without a disability. It is often not until they interact with western systems and institutions that they are required to 'disable' themselves and their rates of participation and performance drop.

"[For people living on country and in their communities, the notion of segregations is] totally alien to people. Everybody lives with their family, your identity comes from your family, who you're related to out in the community. It's like a big web of support in terms of everybody being related to everybody else and people know what's expected of them in community because of that web." – Disability Advocacy Network Australia (DANA)[373]

3.4.4. Failure to meaningfully embed cultural safety is facilitating experiences of racism and discrimination in service delivery

Western concepts of governance that require risk and compliance-based approaches that encourage distance (physical, emotional and social) between clients and staff undermine inclusion and cultural safety.[374] This is at odds with First Nations approaches to governance, which are based on close relationships and social roles.[375] Disability organisations, including Aboriginal Community-Controlled Organisations must navigate this contradiction every day under governance processes and reporting requirements that do not account for, measure and encourage culturally safe care. This can cause confusion in applications of First Nations led practice, undermining existing efforts to deliver culturally safe services.

"Aboriginal and Torres Strait Islander peoples have been surprised by initial NDIA staff contact and experience confusion and fear about meeting outcomes..." – Lowitja Institute[376]

The failure to embed cultural competency at all levels, such as in relevant governance structures, legislation, the NDIS Code of Conduct, the NDIS Practice Standards, or the NDIS Worker Orientation Module has facilitated the delivery of culturally unsafe services, leading to repeated experiences of discrimination.

"I have had issues with racism and discrimination from service providers. It has been almost impossible to find culturally safe supports in my region." – First Peoples Disability Network Australia[377]

These experiences of discrimination reinforce and uphold feelings of 'apprehended discrimination' that then extends beyond the original discriminatory incidents and impacts future help-seeking behaviours and service delivery interactions.

"Frequent exposures to various forms of discrimination can have a cumulative impact and can manifest into 'apprehended discrimination'. This is a pathway in which a fear of discrimination transforms into a rational expectation of discrimination, and it can lead to a person avoiding social situations where they could be exposed to possible discrimination." – Scott Avery[378]

During the NDIS Review, the First Peoples Disability Network conducted engagement surveys with First Nations people which found:

"...a lack of cultural competence among the NDIS workforce greatly impacted the experiences of First Nations participants. In a question about whether participants felt culturally safe in NDIS interactions, an overwhelming 66.7% said 'no' and when asked about what the NDIS should know, a number of participants described a need for a culturally competent workforce." – First Peoples Disability Network[379]

This also revealed a need to:

"...develop a workforce that is culturally aware" – First Peoples Disability Network [380]

We have heard a willingness of people wanting to know more about trauma-aware and culturally informed approaches that recognise this disconnect between First Nations and non-Indigenous ways of being, doing, and seeing disability. Providers and advocates want to meet the needs of their clients.

"Everything is rooted in the loss of identity, culture, removal of their lands, the trauma across generations. And a lack of understanding of presentation of trauma ... As an advocate, I would like to be better equipped and be able to be linked with the First Nations services and have training... That's a starting point for me, that there needs to be work done right across every sector of society for our First Nations people. Yes, there has been some improvement, but a lot is minimal. I think there is a fuss made that the government has done this or that, but it is minimal compared to what needs to be done, the investment that needs to be made." – Disability Advocacy Network Australia (DANA)[381]

3.4.5. There is a disconnect between current disability and First Nations policy settings

The disability ecosystem has traditionally used siloed approaches for policy, workforce, education and employment approaches. We have identified a demonstrated need for a more holistic and interconnected approach to disability policy to improve outcomes and realise the rights of all people with disability.

For First Nations people with disability this fundamental problem of disconnected and disjointed approaches is magnified due to a lack of coordination and accountability across the intersection of disability and Closing the Gap policy, programs and investments. "The endorsement of both the National Agreement and the Strategy by all levels of government in the past two years presents a unique opportunity to drive national action and improve outcomes with and for First Nations people with disability."[382]

The National Agreement on Closing the Gap (2020) sets the agenda for First Nations reform, outcome measurement and investment. The ADS sets the agenda for disability reform, outcome measurement and investment. The cross-cutting nature of these frameworks means that both cover a range of socio-economic outcomes areas such as employment, education, safety and justice. However, both have failed to meaningfully recognise and embed the other.

> *"We require both DSS and NIAA to jointly own this [First Nations disability policy] as until Closing the Gap and Australia's Disability Strategy both address this, FPDN are lumbered with the cross-cutting coordination of government strategies, which is not our role." – First Peoples Disability Networks* [383]

For First Nations people with disability this creates a fundamental disconnect in the way government operates, how services are funded and how the voices of First Nations people with lived experience of disability are centred in policy.

3.4.6. More needs to be done to achieve the intent of Closing the Gap's Disability Sector Strengthening Plan

In 2022, the Australian Government published the Closing the Gap, Disability Sector Strengthening Plan (Disability SSP). The Disability SSP was developed in genuine partnership with First Nations people with disability and all states and territories. The Disability SSP and its associated First Nations-led Guiding Principles lay the foundations for strong, culturally inclusive and responsive disability service sector (see Chapter 4 and Recommendation 14).[384]

 However, there remains real gaps in realising the actions and ambition set by the Disability SSP. The Productivity Commission's Review of the National Agreement on Closing the Gap (Draft Report) calls out some limitations of the Closing the Gap Sector Strengthening Plan and the current approach to implementation, concluding that:[385]

- It is not clear whether they promote transformational, short-term change or business-as-usual
- Actions listed may not be specific enough to push government parties toward transformative reform
- Strong accountability mechanisms are required to ensure commitments have been followed through and actions are implemented
- Many actions are only defined at a high level, without concrete timeframes, responsibilities and resources

> *"The initial round of SSPs do not articulate a clear conceptual logic of how the listed actions will improve outcomes for Aboriginal and Torres Strait Islander people. Furthermore, the effectiveness of the SSPs will depend in part on the strength of partnerships – not only in their development, but also as part of promoting ongoing accountability and alignment with policy partnerships." – Productivity Commission* [386]

These limitations have resulted in a reliance on further development of specific partnership mechanisms. However, unlike other areas (housing, early childhood and health) identified for sector

strengthening, disability does not have a dedicated policy partnership (see Closing the Gap Priority Reform 1[387]). This leaves a real accountability gap that is limiting progress, a further development of actions, widespread uptake and implementation of the Disability SSP.

This has in turn left First Nations people with disability, the relevant representative organisations and First Nations peak bodies with no dedicated over-arching mechanism to:

* Progress the development of actions in partnership with the sector and governments
* Monitor and measure implementation
* Hold governments to account on progress.

3.4.7. A lack of national direction and attention means the needs of First Nations people with disability are often de-prioritised or not considered at all

There is an agreed recognition for the need of dedicated approaches for addressing First Nations outcomes across health and social policy. Dedicated national strategies or 'Action Plans', agreed by all jurisdictions that focus solely on achieving sustained improvements to the lives of First Nations people are commonplace. For example:

* Safe and Supported: Aboriginal and Torres Strait Islander First Action Plan 2023-2026[388]
* Aboriginal and Torres Strait Islander Action Plan 2023-2025, Under the National Plan to End Violence against Women and Children 2022-2023[389]
* National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023[390]
* National Aboriginal and Torres Strait Islander Health Plan 2013-2023[391]

However, First Nations-led and coordinated national practice is missing across the disability ecosystem. Many organisations across the Aboriginal community controlled sector have called for the inclusion of a NDIS specific target to be included under the National Agreement on Closing the Gap, hoping that would drive the prioritisation of First Nations people throughout disability policy.[392]

However, the need to draw together a coordinated approach to improving the lives of First Nations people with disability remains. There is no current NDIS or disability target under the National Agreement on Closing the Gap, noting the Australian Government has committed to disability as a cross-cutting policy priority under the Commonwealth Implementation Plan on Closing the Gap.

Additionally, the lack of a dedicated target or overarching strategy that articulates a First Nations disability ecosystem (inclusive of Closing the Gap) has led to inconsistent and disjointed measurement and monitoring of outcomes for First Nations people with disability.

3.4.8. A national coordinated effort that recognises and affirms First Nations concepts of disability and care is needed to drive culturally safe reform across a First Nations disability ecosystem

Culturally responsive and safe services for First Nations people with disability should be informed by cultural models of inclusion. This inclusive and tailored approach should be championed though

dedicated and coordinated efforts to improve consistency in culturally safe delivery. A commitment to this approach should be embedded into existing mandatory training requirements, practice guidelines and policies, protected by legislation (where appropriate).

To be successful, a national effort that builds on the initial success of the Disability SSP and the Priority Reforms set forth by the National Agreement on Closing the Gap is required, alongside the First Nations Schedule in the Disability Intergovernmental Agreement (see Action 20.4). Prior to the establishment of the First Nations Disability Forum (see Action 20.4) efforts should be led by the First People Disability Network as the Disability Representative Organisation working closely with other key groups such as Aboriginal Community Controlled Health Organisations and their representative organisations, recognising that they are community controlled, have an on-the-ground presence in communities and significant expertise beyond health.

3.4.9. Action & Implementation Details

Action 2.10: The Australian Government should develop a national strategy to improve the quality of the disability ecosystem for First Nations people with disability

Designed and implemented in partnership with a new First Nations Disability Forum (see Action 20.4), the national strategy will address persistent gaps in the investment, coordination and development of culturally accessible and safe services for First Nations people with disability. It would also facilitate performance monitoring for First Nations people with disability against Australia's Disability Strategy (ADS) and the National Agreement on Closing the Gap (Targets and Priority Reforms). The national strategy should prioritise the implementation of actions already identified by the Disability Sector Strengthening Plan and the forthcoming National Disability Insurance Agency First Nations Strategy.

Implementation detail:

- The Department of Social Services (DSS) should develop a First Nations Disability Strategy to coordinate action, investments and measure outcomes of First Nations people with disability across the First Nations Disability ecosystem. This includes the NDIS, foundational supports, disability employments services, advocacy, and outcomes under ADS and the Closing the Gap.
- The new First Nations Disability Strategy should be based on an anti-racial ableism approach that facilitates truth-telling and commits to building capability to overcome systemic inequality across the life course. It should include:
  - A commitment to develop a First Nations Disability Performance Framework (the Performance Framework) to independently monitor the strategy

- Support for the development of mechanisms to identify and eliminate institutional discrimination (racial ableism)

- A review and strengthening of cultural accessibility and competency standards for disability service grant recipients targeting First Nations cohorts, Australian Government grants targeting First Nations people with disability, NDIS providers, the NDIS Code of Conduct, the NDIS Practice Standards, the NDIS Worker Orientation Module and Worker Screening Check processes

- Development of dedicated actions to improve outcomes for First Nations people with disability across all socio-economic targets under Closing the Gap and outcomes areas under ADS with particular attention to health (specifically regarding access and diagnosis), employment (with a focus on youth), education and housing areas establish a program of work, including pilots, focussing on early intervention for children and young people and the justice system or in communities of high incarceration rates

- Targeted and measurable workforce strategies to grow a highly skilled, culturally safe and inclusive First Nations Disability workforce (as part of broader disability workforce strategies)

- A commitment and pathway forward for embedding culturally responsive and accessible practice to lift quality in service delivery for First Nations people with disability across the Australian Public Service

- A commitment to developing and implementing First Nations disability-led evaluation best practice guidelines.

All inclusions should be specific, measurable, outcomes-based and time limited to ensure the appropriate level of accountability.

- DSS should lead the development of a First Nations Disability Performance Framework (the Performance Framework) alongside the national strategy that independently monitors the socio-economic outcomes of First Nations people with disability against Closing the Gap Targets and Outcome Areas of the ADS.

- The Performance Framework should be developed in partnership with First Nations disability academics, community and policy experts. Once complete it should sit alongside the Productivity Commission's Closing the Gap reporting responsibilities.

- DSS should work in partnership with the Australian Institute of Health and Welfare to ensure that relevant linkages, identified gaps and representations of the First Nations Disability Performance Framework are reflected in the Outcomes Framework, the Outcome Framework website, Data Improvement Plans, the National Disability Data Asset and online hub of the ADS.

- DSS should work with the National Indigenous Australians Agency and the Productivity Commission to ensure that the First Nations Disability Performance Framework is

appropriately linked and reported on throughout relevant annual Closing the Gap reporting mechanisms and data development plans.

3.5. The education system is not always inclusive, accessible or well connected with the NDIS – leading to a lack of consistent and fair support for children in early childhood education and care and schools

The Australian Government and state and territory governments have a shared responsibility for supporting children with disability in early childhood education and care and school education settings. Unfortunately, this shared responsibility has not translated to consistent, fair and appropriate supports for children in education settings.

While the benefits of inclusive early years and school education are well known, many children continue to face significant barriers to being included on an equal basis with their non-disabled peers. For school aged children with disability, we have been shocked to hear about the current extent of low attendance, school refusal, home schooling and no schooling.

There is also significant confusion over responsibilities of the NDIS and the early childhood and school education systems. This creates barriers to children accessing the right supports, can contribute to poorer social and economic lifetime outcomes, and in some cases an increased reliance on the NDIS to fill support gaps in mainstream education settings.

3.5.1. More inclusive education delivers better outcomes for children with disability, but educational settings are not as inclusive as they should be

Despite strong supporting evidence for inclusive education, children with disability continue to face barriers in the early childhood and school education systems, limiting their ability to participate equally and achieve their full potential.

The Disability Royal Commission has reported that the number and proportion of children with disability in Australia is increasing.[393] This is leading to an increased need for educational settings that can meet the diverse needs of disabled students. Data from the Nationally Consistent Collection of Data (NCCD) on School Students with Disability suggests that around 878,000 students in Australia have a disability, and that around 46,700 are enrolled in special schools.[394] Mainstream schools therefore have the primary role to support students with disability and learning difficulties.

Inclusive and accessible education encompasses having both the facilities and the culture that enables desired learning outcomes for all children.[395] One of the goals of ADS in education and learning is to 'build capability in the delivery of inclusive education to improve educational outcomes for school students with disability.' [396]

Data suggests that while all children benefit from quality pre-school education, it has particular benefits for children from disadvantaged backgrounds. Pre-school education can boost children's confidence, social skills and provide a better foundation for success at school. Recent data analysis in NSW found attendance at community preschool improved the likelihood of a child obtaining the National Minimum Standard for Grade 3 NAPLAN.[397]

Despite the strong evidence on the benefits of inclusive education, Australia continues to lag with many students with disability excluded from their neighbourhood schools. There are many barriers including:

- Children facing challenges accessing inclusive settings early in life – for example children from disadvantaged backgrounds, including children with disability, are more likely to be developmentally vulnerable and less likely to participate in early childhood education and care.[398]
- Difficulties with caring arrangements – the evaluation of the Inclusion Support Program, conducted by the Australian Institute of Family Studies in 2021, found around 1 in 5 parents of a child with additional needs reported having to change childcare because of issues with care, double the rate of parents without a child with disability. [399]
- Lack of support for students with disability can lead to families and caregivers choosing to educate at home – for example in Queensland, registrations for home education in primary year levels increased by 137 per cent from 2018 to 2022, with this increase more significant for high school aged students. As at 5 August 2022, around 8,500 students were registered for home education in Queensland.[400]

The evaluation of the Inclusion Support Program also noted there were inherent tensions surrounding approaches to inclusion and it being contested, with different understandings of whether the service should fit the child, or the child should fit into the service.[401]

Australia maintains a dual track education system where students with disability are educated either in mainstream schooling or in special schools, special education units, or homes where they are separated from their non-disabled peers.

> *"Students with disabilities do not access the conventional pathway to employment whilst at school and are directed to either congregated or unrelated programs once school is completed such as day programs (usually filled with time wasting activities rather than genuine progression to employment or community inclusion)." – National Alliance of Capacity Building Organisations [402]*

The Disability Royal Commission concluded that education in Australia is not sufficiently inclusive and that it should be improved. While the Commissioners were split on the details of the pathway to a more inclusive system and the role of specialised schools for children with disability, they agreed that 'all Australian governments and educational authorities should address and progressively overcome the barriers to inclusive education in mainstream schools.' [403]

Poor educational experiences and outcomes for students with disability can put them on a separate trajectory from their peers. A lack of inclusion during the school years increases the likelihood of students with disability also entering segregated environments in housing and employment as they leave school. This can lead to an increased reliance on specialist disability support in the long term, increasing the cost of the NDIS.

3.5.2. The relationship between the early childhood and school education systems and the NDIS is disconnected, complex and hard to navigate

While all governments have a shared responsibility for supporting children with disability in educational settings there is not a fully joined up approach to supporting children across systems, including with the NDIS. This can lead to a complex web of eligibility criteria, inequity with 'winners and losers' at the most critical times and stages of development and increased pressure on the NDIS.

Early childhood education and care

Early childhood education varies by jurisdiction, with some run directly by state and territory governments while in other jurisdictions they are funded by state and territory governments and run by community-based providers or have a hybrid arrangement.[404]

Navigating competing information and viewpoints in this space can also be difficult for parents and policy makers. The NDIA Early Childhood Reset Project highlighted that early childhood interventions may end up overlapping with the responsibilities of early childhood education and care where children are withdrawn from universal services to participate in intensive therapeutic programs.[405]

These challenges are well known to government. There are several reviews and reforms underway to strengthen early childhood education and care for children with disability, including:

- The Productivity Commission Inquiry into the early childhood education and care sector, which seeks to address making early childhood services more affordable and accessible for families and children and improve outcomes for children and families experiencing vulnerability and/or disadvantage, including children and families experiencing disability. A final report will be provided to government by 30 June 2024.[406]
- Federal, state and territory education and early year's ministers are developing a national long-term vision to drive future reform of early childhood education and care.[407] The draft vision acknowledges the learning and development benefits of early childhood education and care and its additional significance for children from vulnerable and disadvantaged communities. National Cabinet is expected to consider the vision in late 2023.
- The Early Childhood TAP under ADS.[408] The TAP focuses on children from infancy to school age with disability or developmental concerns, their families and carers. The TAP sets out key actions to strengthen early identification, information, supports and pathways, as well as collaboration between programs and services, all of which contribute to the development and

wellbeing of children to help them thrive across and between life stages. Actions under the TAP are funded until the end of the 2023-24 financial year and include:

- Increase awareness of the rights and obligations for early childhood and education and care settings to be inclusive of all children, including amending the Disability Standards for Education 2005 to include early childhood education and care (TAP Action 2.2)

- Negotiation of the new preschool agreement to consider the needs of children with disability (TAP Action 2.3)

- Develop educator resources to support inclusion (TAP Action 2.5).

School education

Students with disability can also face barriers accessing appropriate supports in schools. The school education system is responsible for supports where the main purpose is to learn, study and achieve educational outcomes.[409] This includes:

- Learning assistance (this may include teachers' assistants), and inclusion support (for example Auslan interpreters) to enable the participation of students with disability in education services, in line with reasonable adjustment
- General support, resources, training and awareness building for teachers and other school staff to support and engage students with disability at school and in the classroom
- Making sure the school building and facilities are accessible and ensuring all curriculum activities are inclusive, such as camps and sporting activities
- Providing transport between school activities, such as to excursions and sporting carnivals.

The Schooling Resource Standard implemented after the Review of Funding for Schooling (Gonski Review) provides for needs-based funding. Extra funding is provided based on the number of disadvantaged students in a school, including students with disability. This funding is informed by NCCD data on school students with disability. It should be noted that the allocation of this funding is decided by educational authorities and/or at a school level. Its usage and transparency therefore can vary considerably.[410]

Despite needs-based funding, data on children with disability enrolled in school across Australia is problematic. In the most recent Report on Government Services (ROGS), the Productivity Commission reported that in 2019, one in five or 19.9 per cent of Australian students received an educational adjustment due to disability (around 775,000), with 4.8 per cent of students requiring extensive or substantial adjustments (around 185,000).[411] However, the Productivity Commission noted 'state and territory government data on children with disability are not directly comparable because the definition of disability varies across jurisdictions.'[412]

Improved data and transparency are desirable from a policy perspective, as it would enable better policy making, better performance reporting, and make clearer where people are facing issues within the current system.

Families and students often need to go through complex assessment processes to receive funding. Funding models can often be inflexible, and some students may miss out on vital support as a result.

> *"Many parent carers spoke about how they had turned to home-schooling after experiencing a lack of support and understanding. They reported feeling that the schools did not provide a safe and inclusive learning environment for their child." – Carers Tasmania [413]*

It is not always clear to parents whether support should be provided by the school or the NDIS. Where schools may not provide adequate support, parents can turn to the NDIS to fill the gaps. This means support may not always be delivered in the most appropriate setting or in the most effective way. Resource constrained schools might also encourage parents to use their NDIS funding in different ways.

> *"Some schools are unwilling to have early childhood early intervention specialists or allied health professionals enter the school, especially when they may have their own resources. This may lead to a disconnect in service delivery if children are not able to access those services in a school setting, or if they see one practitioner at school and another in the community." – Early Childhood Intervention Best Practice Network [414]*

Confusion is further exacerbated by the fact that some supports in schools are funded by the NDIS. The NDIS is responsible for some supports that children with disability require due to the functional impact of their disability, but which is not specific to an educational setting, including: [415]

- Personal care and support at school
- Transport, including to and from school
- Specialist support to transition to higher education, training or work.

Confusion also exists over the provision of capacity building supports within school hours.[416] There is currently a lack of clarity and inconsistent practice about how NDIS providers should work in school grounds. Parental choice means that families can choose to have supports delivered while their child is at school. This has the potential benefits of supports being delivered in a natural setting and a therapist working as part of a normal routine with the child. However, these benefits are not realised if children are removed from the classroom to receive these supports.

We have heard the focus of therapy is frequently on working 'with the child' rather than working with the educators to build their capacity to include the child and other students with disability. This approach creates further barriers to full participation of children with disability in schools.

> *"These [community based services, e.g. schools, playgroups, social welfare organisations, recreational, community health services] services are not getting the degree of support from ECI providers that they had before." Professionals and Researchers in Early Childhood Intervention [417]*

We have also heard that schools are struggling with managing and coordinating multiple therapists on their grounds. Some schools can receive dozens and indeed in excess of one hundred requests for access from therapists. From the school perspective, understandably, this is seen as disruptive to the delivery of the curriculum.

Schools receiving many requests for access to students is in part due to the individualised nature of NDIS funding, significant growth in therapy supports and fragmentation of the therapy market. This has seen the number of individual providers increase and a lack of recognition that a key role for therapy for children of school age is assisting teachers and schools to make the curriculum accessible for each child. Ideally, there should be an agreed statement of goals between NDIS plans and school Individual Education Plans.

> *"When our son was first diagnosed, he was 3y3m and in an early childhood education centre. The director, upon hearing the news he'd been diagnosed, suggested that we engage a support worker/aide using our NDIS funding to come to the centre every day. She said "this is what other families have done". When we did our own research and discovered that it would not be permissible to use our funding this way, the director became hostile and said she couldn't afford to pay an extra educator to care for our son. I have since learnt that this attitude is rife, with preschool staff at varying levels regularly suggesting that NDIS should fund things that are actually the education provider's responsibility. If the class is going on an excursion and my son needs a 1:1 carer so that he can participate in the nature walk, it is the centre's responsibility to pay for this, not the NDIS. With a diagnosis, our son is set apart from other children. He is "different". The local Catholic school denied him admission because he is autistic. They didn't want to pay for an aide. They said "he needs to go to school, but there are special schools for kids like that". The local government school has refused to allow our NDIS-funded therapists to attend the school "because it's against school policy". They suggested our speech therapist could write a letter setting out recommended techniques to help our son's communication, but she's not allowed to come into the classroom. Speaking to other parents, I understand this varies widely and in some schools, therapists are welcomed." – Carer [418]*

In the future, children and families in the NDIS should have support from lead practitioners to coordinate supports and manage the team around the child. This means schools will benefit from greater coordination of supports by the lead practitioner and have less points of contact to manage. More detailed information on how the lead practitioner should support children with disability and development delay, including in school settings is outlined in Recommendation 6.

3.5.3. Reform is required to ensure the school education system is more inclusive and accessible and better connected with the NDIS

To ensure children receive consistent, fairer and appropriate in early childhood and school education settings across Australia, we recommend:

- The development of a national plan by the Australian Government and state and territory governments that ensures the NDIS and school education system are connected, complementary and focused on better educational outcomes for all children with disability. This should include:

  - Identifying ways to better support families and caregivers understand and navigate the education system and interface with the NDIS

  - Clarifying the approach for Lead Practitioners (contracted by the NDIA) to coordinate the delivery of supports on school grounds, including the approach to working with early education or schools to build their skills and capacity to support children with disability in these natural settings, and to prepare for upcoming transitions

  - Better integration of the NDIS into schools to enable educators to feel better supported, make reasonable adjustments and ensure the curriculum is accessible for diverse learners

  - Considering how an approach to trialling the provision of NDIS group-based supports on school sites after school hours could be implemented.

- All governments should prioritise initiatives that protect and promote the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools. This should include the Australian Government:

  - Enacting legislative change to define and guarantee the right to an inclusive education

  - Leading the development of a roadmap and action plan for achieving inclusive education in Australia

  - Introducing mechanisms to embed greater accountability and monitoring of schools' compliance with legal obligations relating to inclusive education. This should include requiring states and territories to publicly report on the use of needs-based disability loading funding from the Australian Government

  - Training for all education staff to across all jurisdictions to understand the laws, policies, programs and universal design for learning approaches of teaching

  - Consider encouraging schools to use specialised tools to measure educational progressions for students with disability.

These reforms should be complemented by:

- Implementation of Lead Practitioners for children younger than 9 with a NDIS plan (see Action 6.5), as well as time limited Lead Practitioner support in foundational services (see Actions 1.12 and 1.13). A key function of Lead Practitioners will be to coordinate the team around the child, which will include early education and schools. Lead Practitioners will support children and families through transition points such as starting school, transitioning to high school or to further education and employment

- The development and trial of a mechanism to publicly communicate the performance of current Disability Standards under the DDA (see Action 2.3). This mechanism should be easy to find,

easy to understand, and allow people to know whether a service is delivering at a higher quality than the minimum standard, such as a star rating system. We recommend that the Disability Standards for Education be considered as a starting point for this trial, noting that we have also recommended that the Disability Standards for Education which were codified in 2005 should also be reviewed (see Action 2.5)

- The expansion of universally available child development checks to mainstream settings, including a consistent minimum level of developmental monitoring over children's ages and stages to ensure the early identification of children with developmental concerns and disability and enable early intervention (see Action 2.13). This will ensure that children with development concerns and disability are consistently identified early across all jurisdictions, including in school settings

- The ceasing of 'in-kind' arrangements in the NDIS for specialist school transport and personal care in schools (see Action 2.16). We recommend that specialist school transport and personal care in schools should be removed from the NDIS and returned as state and territory government responsibilities.

3.5.4. Action & Implementation Details

Action 2.8: The National Disability Insurance Agency and the Department of Education, with state and territory education and disability agencies, should develop a plan to better connect the NDIS and school education system and improve educational outcomes for children with disability

This should be focused on ensuring consistent, fair and appropriate support arrangements for participants in school settings across Australia. The plan should outline how the school education system and NDIS will work together to ensure funding and supports are complementary, connected and outcomes focused to achieve shared goals for all students with disability. This could include schools operating as hubs within the community to host delivery of NDIS funded services after hours. The plan should also outline options for how to better plan, coordinate and streamline NDIS funded supports in school settings and share and agree goals. The plan should sit as part of a dedicated Memorandum of Understanding for the school education and NDIS interface (see Action 2.6).

Implementation detail:

The NDIA and the Australian Government Department of Education, with state and territory governments, should also as part of this plan:

- Identify approaches to better support families and caregivers understand and navigate the education system and interface with the NDIS
- Determine appropriate service requirements for Lead Practitioners (to be commissioned by the NDIA) for engaging with early education and schools, including how they

coordinate service delivery on-site and work with staff. This needs to recognise that Lead Practitioners are the agent of the child and family and must act in their interests and wishes. Everything possible should be done to ensure a coordinated approach but on occasions parental choice may clash with the preferred approach of an early education provider or school. Ideally, every child with a disability should have a jointly agreed statement of educational support needs with agreed support arrangements.

- Identify opportunities to trial and test new approaches for funded supports in school settings outside of school hours
- Consider how a pilot program of schools as hubs could be developed, and gauge interest from communities and schools that may wish to be part of such a pilot.

Action 2.5: All Australian governments should take steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools

Existing legislative instruments should be strengthened to clearly define inclusive education and include stronger accountability and monitoring of schools' compliance against their legal obligations. The needs-based disability loadings each school receives and the use of that funding to benefit students with disability should be reported publicly. The overall performance of schools against their legislative and financial obligations should be measured and publicly reported. This should be supported by greater training for all education staff to understand the laws, policies, programs and inclusive education approaches to teaching and learning.

Implementation detail:

Education Ministers should:

- Prioritise the development of a roadmap and implementation plan to deliver inclusive education within Australia (National Roadmap to Inclusive Education). This should include an approach to:

  - Agreeing a nationally consistent definition for inclusive education

  - Identifying legislative amendments across jurisdictions required to consistently protect the right to inclusive education

  - Ensuring children with disability are fully included with the right adjustments and levels of support in universal settings alongside their non-disabled peers

  - Transforming culture, policy and practice in all educational environments to accommodate the different requirements and needs of individual students, including commitments to removing barriers that prevent that possibility

- Taking steps to reduce suspensions, exclusions, expulsions and eliminate all restrictive practices.

- Agree an approach to regularly reporting on progress implementing the National Roadmap to Inclusive Education and monitoring progress towards its objectives, including:

  - Collecting and reporting on educational experiences and outcomes of students with disability and developmental concerns. This will need to include data collection and reporting relating to gatekeeping, suspensions, exclusions, expulsions and any cases of restrictive practice

  - Measuring and reporting individual school performance against their legislative obligations. This will need to include agreed metrics to measure the extent obligations to provide inclusive education are being met

  - Consistently reporting on the needs-based disability loading received by states and territories, and how that funding has been used to benefit students with disability.

The Australian Government should:

- Enact legislative change to ensure rights to inclusive education are upheld
- Ensure that disability loading settings and inclusion support funding remains adequate to support the participation of children with developmental concerns and disability in early childhood education and care.

The Australian Government, together with state and territory governments, should:

- Develop and report on measures relating to inclusion in education
- Implement a national professional development system to support early childhood educators, educators and teachers with the necessary training, skills and guidance to provide inclusive practice and adjustments for disability within usual practice
- Develop mechanisms to ensure needs-based funding is implemented and reported on.

The Productivity Commission should expand the Report on Government Services to include indicators in the:

- Early childhood education and care dataset relating to the exclusion and participation of children with developmental concerns or delay
- School education dataset relating to attendance, attainment, retention and destination of children with disability. This should be broken down to include the type of education setting (home schooling, distance education, mainstream setting, segregated setting in a mainstream environment, segregated education)
- School education dataset relating to exclusion, suspension, any cases of restrictive practice and expulsion rates of children with disability.

3.6. The NDIS needs a long-term transport policy that better supports the mobility needs of participants and complements accessible public transport systems

3.6.1. A coordinated and consistent approach between transport systems and the NDIS is required to better support the mobility needs of people with disability

Transport systems and local governments are responsible for transport infrastructure to meet the needs of all Australians, including those with disability. This includes infrastructure such as roads, footpaths, train lines, waterways, and disability parking. They are also responsible for making sure public transport, such as stations, stops and vehicles like buses, is accessible for people with disability.

The NDIS is intended to complement accessible transport systems. The NDIS does this by supporting NDIS participants to travel independently, such as training to use public transport, or assistive technology to help with travel. The NDIS also supports modifications for private vehicles and transport funding for the reasonable and necessary cost of taxis, rideshares or other private transport, for participants unable to use public transport due to their functional impairment.

We have heard transport systems are not adequately accessible for people with disability and these transport systems are not well connected to NDIS funding arrangements. A comprehensive transport policy is required to ensure a coordinated approach that better meets the transport needs of people with disability.

3.6.2. Transport systems are not fully accessible for people with disability

Transport systems should be accessible for all Australians, including people with disability.

States and territories have an obligation to meet accessibility needs through the DDA and the Disability Standards for Accessible Public Transport (these standards are currently being updated).[419] The Standards required making public transport accessible by the end of 2022, and trams and trains by the end of 2032.

Unfortunately, progress towards full accessibility has been slow.[420] Only around 50 per cent of public transportation is meeting the standards outlined in the Disability Standards for Accessible Public Transport.[421] In 2018, only 66 per cent of people with disability considered they could use public transport with no difficulty, a small improvement from 64 per cent in 2012.[422]

> *"My son doesn't drive and we have to drive him everywhere or have to use support workers for transport. Public transport doesn't go all the places he needs to or wants to go to. We can't access the half taxi fares or other schemes as we are not eligible." –*
> *Carer [423]*

Noting the fact that development of infrastructure is a long and involved process, it is evident that progress toward transport accessibility is lagging and not where it needs to be for people with disability. This has consequences for people inside and outside the NDIS. As a service provider said:

"The availability of accessible public transport, for example, does not only affect whether a person can travel from point A to point B but may over time have an impact on their educational and career aspirations, their healthcare, and their personal wellbeing." – Provider [424]

The basic problem is that we have standards and potentially new standards, but they are not being enforced. This is not effective regulation.

Transport disadvantage, or the inability to travel when and where one needs to without difficulty, is a critical issue for people with disability that flows in part from the failures of accessibility outlined above. During consultation for the development of the ADS, 55 per cent of people with disability reported severe or major issues with the availability of 'safe, accessible and affordable transport'.[425] The NDIA is not responsible for the operation of accessible transport systems across state and territories. However, the slow progress toward accessible transport networks coupled with an incomplete approach to funding mobility need in the scheme means many participants experience geographic, physical and economic exclusion.[426]

3.6.3. The approach for determining NDIS transport support is inconsistent, not fit for purpose and requires a new model

Since establishment, the NDIS has essentially adopted the Commonwealth Mobility Allowance (CMA) as the basis of its transport policy.[427] This remains the situation, despite the Productivity Commission saying in 2011 that the flat rate of funding in the CMA was inconsistent with the principles of the NDIS and would need to evolve as the scheme advanced.[428]

NDIA data as at June 2023 shows around 221,000 adult NDIS participants have a transport budget in their plan – around 74 per cent of adult participants.[429]

The NDIS has three levels of support for transport assistance which are used as the basis for determining a participant transport budget. These supports can fund taxis and other similar transportation, support workers to assist with travel, capacity building to be able to use transport, and modifications to participants' vehicles. The three levels of support are indexed annually and as of 2023, consist of:

- Level 1 – Up to $1,606 per annum for participants who want to enhance their community access but are not in work, study or attending day programs.
- Level 2 – Up to $2,472 per annum for participants working or studying part-time (up to 15 hours per week), involved in day programs or other social, recreational, or leisure activities.
- Level 3 – Up to $3,456 per annum for participants unable to use public transport because of their disability and who are working, looking for work, or studying 15 hours or more per week.

Since the scheme commenced, the NDIA has continued to rely on how the CMA was structured to provide support for mobility, rather than developing a new needs-based approach.[430] We have heard from many participants that the NDIS attempting to meet individualised need within a rigid framework has led to uncertainty and poor outcomes for participants. We have further heard about the unclear guidance issued by the NDIA regarding interactions between transport allowances,

CMA and out of pocket expenses.[431] The result has been inconsistent decisions, insufficient funding in participant plans and inequitable outcomes for people with disability:

> *"The rules around use of funds are too rigid, I was allocated a large amount of funds for a support worker, which I will rarely use, and none for travel, which I do need to do regularly to get to employment and medical appointments. The outcome will be $1000s in unspent funds when my plan ends, but I will have borne the financial burden of paying for taxis, etc. to get to employment when my mobility has been too poor to get there by public transport." – Person with disability [432]*

There have been several commitments by governments to develop long-term transport arrangements, as well as developments that have further complicated resolution.

In August 2017 the Federal Court dismissed an appeal by the NDIA against a previous ruling made by the Federal Court in March 2017. This previous ruling made clear that laws governing the NDIS do not allow the NDIA to only partially fund reasonable and necessary supports. The NDIA v McGarrigle case involved a review of a NDIA decision to only part-fund reasonable and necessary transport supports for a participant because of the potential implications for the long-term financial sustainability of the NDIS.[433]

In 2019 Disability Reform Ministers agreed to increase transport funding for NDIS participants who are significant users of state and territory taxi subsidy schemes. Costs associated with reasonable and necessary taxi travel should be met by the NDIS. To guarantee supply while long-term policy arrangements were being developed, state and territory governments agreed to be reimbursed by the NDIA for participants to continue access taxi subsidy schemes.[434]

In March 2022, Disability Ministers agreed to a range of priorities, such as improving planning and assessment processes, designing long-term funding methodologies, and improving participant experiences.[435]

In June 2023, Disability Ministers agreed to 'extend existing short-term transport remediation arrangements to 31 October 2025 while a long-term transport policy for NDIS participants is developed.[436]

Despite this, the NDIS approach to understanding and supporting the mobility needs of participants remains incomplete and disconnected from public transport systems. As a result, long-term issues remain.

3.6.4. The NDIS and public transport systems are not well connected or complementary of one another

In the original design work for the NDIS the Productivity Commission suggested overall transport funding for people with disability using the NDIS would increase, due to taxis being a necessary, but expensive interim option. However, they contended that over time transport cost growth could be moderated through technological advances and expanded community transport.[437]

Governments, researchers and policy makers have long held that community transport, or local and assisted transport, presents a significant but unrealised opportunity to help overcome systemic transport disadvantage. Community transport provides vital services where other transport supply is constrained or non-existent, particularly for older people and people with disability. While there has been some recent innovation in services, some of the key challenges such as fragmented delivery, limited understanding of demand and lack of scale have in part been driven by the shift to person-centred funding of the NDIS and aged care reforms.[438]

In the absence of a better funded and more comprehensive local and assisted transport offering, even with significant fare discounts, the overall costs of using existing public transport for people with disability in and out of the NDIS, assuming it is accessible to them, can be high.[439] We consider that a long-term effective and sustainable NDIS transport policy relies on an enhanced and coordinated community transport offering across states and territories.

While there will always be some people who cannot access public transport options as a result of their disability, the slow progress in achieving accessible transport infrastructure means that state and territory governments and the NDIS more often resort to more expensive individualised options to 'fill the support gap'. For the NDIS, this can be through increasing transport supports in plans. For states and territories, this is partly achieved through taxi subsidy schemes, where financial subsidies are provided to pay part of the cost of taxi fares for people with disability and other eligible people with mobility difficulties.

For NDIS participants, these state and territory taxi subsidy schemes fill part of the gap and are currently funded by the NDIS through cross-billing arrangements with states and territories, as the NDIS was always expected to replace the funding from transport taxi subsidy schemes for participants.[440] The NDIA considers uncapped taxi fares to be unsustainable. But the failure of the NDIA to reform the levels of transport provided in participant plans has resulted in participants relying more heavily on subsidised taxis to fill the gap.

> *"In practice, the maximum amount available under transport funding through the NDIS is significantly less than that provided by state taxi subsidies and is insufficient for most people." – Vision 2020 Australia[441]*

Given the centrality of transport to social and economic participation, reform is urgently needed. A joint, concerted effort is required to develop and implement a long-term transport policy that provides clarity and consistency. As part of this, the NDIS rules and operational guidelines on what transport costs can be claimed by participants and providers require clarification.

3.6.5. A NDIS transport policy is critical to provide clarity and consistency in how the NDIS supports participants' mobility needs, and is better connected with the transport system

Given the complexity of the task and their considerable NDIS, transport pricing and regulation and market design experience, the Productivity Commission is best placed to review existing issues and develop a long-term NDIS transport policy. The transport policy should enable the NDIA to develop and use appropriate measures to assess mobility need. It should provide clear and

consistent definition of the difference between ordinary living expresses and additional disability-related costs and describe clear and consistent guidance on the provision of transport related capacity building.

The policy should:

- Develop and provide options for how a credible assessment of participant mobility needs can be implemented, particular for those that are unable to use other transport options due to the complexities of their needs. This is addressing the needs of a participant resulting from their disability
- Develop and provide options for how a mobility assessment would factor in the availability and accessibility of public transport in a participant's location. This is addressing the needs of a participant resulting from where they live, work and socialise
- Develop and provide options for how transport supports could be purchased in ways that generate customer records and don't involve simply providing cash payments to participants
- Identify how availability can be addressed in supply constrained markets, such as regional and remote areas. This is likely to include the need for increased availability of community transport and point to point services
- Better delineate the supports and costs that will be covered through the NDIS and should be covered through transport systems
- Ensure transport supports can be tailored to the needs and circumstances of the participant
- Ensure consideration is given to the role of the NDIA as a co-steward in transport systems. Specifically, the NDIA should have a limited but important role in supply-side stewardship, where NDIS participants represent a significant proportion of specific segment demand, such as where many NDIS participants need to access wheelchair accessible taxis, meaning transport agencies and the NDIA must work together to ensure ongoing supply of these critical services
- Facilitate and drive ongoing innovation in transport supports.

As applicable, the details of the transport policy should be reflected in revised roles and responsibilities in the new multilateral schedule (see Action 2.6), along with any appropriate changes for adjacent transport supports. Finally, there should be a cessation of current cross-billing arrangements for taxi transport subsidy schemes in line with the implementation of the long-term transport policy.

3.6.6.   Action & Implementation Details

Action 2.9: The Productivity Commission should develop a NDIS transport policy that better meets the mobility needs of participants

The policy should define mainstream transport systems and NDIS responsibilities and outline how they should work together to ensure people with disability are able to move around in their local communities. The policy should also update current systems for determining mobility

needs with a needs-based, individualised assessment that has a clear and consistent distinction between ordinary day living expenses and additional-disability related costs, along with transport-related capacity building. Following the development of the policy, the National Disability Insurance Agency in collaboration with state and territory governments will be responsible for implementation. Implementation of the new policy will include cessation of the current taxi subsidy cross-billing arrangements.

Implementation detail:

To ensure the transport policy is robust and implementable and developed as a priority, the Disability Reform Ministerial Council should:

- Establish a transport tasking group to oversee the development, approval and implementation of the NDIS transport policy. The group should be chaired by the Department of Social Services and include executive representation from state and territory transport agencies.
- Request a project plan from the Productivity Commission be developed consistent with the guidance provided in supporting analysis from the NDIS Independent Review.
- Agree to provide funding from the Department of Social Services to the Productivity Commission to deliver the policy design project. Funding should be sufficient to provide a core team within the PC and external experts to join the project, including from the iMove Cooperative Research Centre, the University of Technology Institute for Public Policy and Governance and Intelligent Transport Systems Australia.
- Request periodic updates from the Productivity Commission project lead to ensure scope, quality and timeliness of delivery.

3.7.   There is friction at the interface between the NDIS and aged care system - resulting in poor outcomes for some individuals, inequities and longer term sustainability risks for the NDIS

As all people age, the likelihood they develop disability or further disability increases, and their support needs may change. However, the NDIS was never meant to replace the aged care system - they were meant to work together so that people with disability could receive appropriate support as they aged. The NDIS and the aged care system working better together should ensure greater equity and dignity for older NDIS participants and improve the NDIS and broader system sustainability.

3.7.1. The NDIS and the aged care system have been set up in similar but different ways, creating a challenging interface between the two

The NDIS and the aged care system both provide supports to meet people's disability needs, but their design and funding arrangements are different in many key respects. This is creating friction between the two systems, resulting in poor outcomes for some individuals, inequities, and longer-term sustainability risks for the NDIS. This reflects a deliberate choice in the design of the NDIS, as recommended by the Productivity Commission in 2011, to provide social insurance for disability that is acquired at birth or earlier in life and more difficult to predict, rather than for disability that is increasingly likely to be acquired as a person ages.[442]

As a lifetime scheme, participants who have been determined eligible under the age of 65 can continue to remain in the NDIS once they turn 65. However, when an NDIS participant turns 65, if they can choose to enter a permanent home care arrangement or residential aged care, they must cease to be a NDIS participant.[443] For this policy intent to work in practice it relies on an aged care system that can appropriately meet the disability needs someone has lived with and the disability needs that will emerge as they age.

The evolution and objectives of the aged care system are geared to meet the needs of older people, including impairment associated with ageing.[444] Aged care is generally only available for people aged 65 or over, with exceptions for First Nations people and people who are homeless or at risk of homelessness who may be able to access aged care from age 50.[445] People generally access the aged care system at around 80 years old, when they are more likely to have a significant functional impairment.[446] While there are some younger people in the existing aged care system, there is an objective for no-one under the age of 65 to enter the aged care system in the future (see Box 8).

Entry into the aged care system is based on functional assessment, the type and intensity of which varies depending on a person's likely needs.[447] In 2022-23, around 4.6 million Australians were over the age of 65, and around 1.2 million Australians were using aged care services.[448] As June 2022, around 185,000 people used residential aged care (RAC), around 215,000 received an in-home care package (Home Care Package – for example regular complex support) and the rest in the aged care system use in-home support for help with just a few services (Commonwealth Home Support Programme).[449]

Box 8: Younger people in residential aged care (YPIRAC)

The Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission) recommended in their Final Report that no people under 45 should be in residential aged care by 2022, and no people under 65 by 2025.[450]

Residential aged care is considered inappropriate for younger people (except in exceptional circumstances), as it is designed for an older cohort, and may lead to decreased quality of life for younger people due to social isolation.[451]

Of the 2,423 younger people living in residential aged care at 31 December 2022, 2,153 had an approved NDIS plan.[452] However, not all young people in residential aged care are eligible for the NDIS or have a disability.[453]

There are measures in place that aim to ensure younger people are not approved for residential aged care, unless all alternative options are exhausted, and to reduce the number of younger people in residential aged care. This includes changes to the entry pathway to aged care with the recently introduced Principles and Guidelines for a Younger Person's Access to Commonwealth Funded Aged Care Services.[454]

AIHW data shows that while the 2022 targets have not been met, numbers have declined for each target, noting this also accounts for ageing and mortality.[455] Joint action is required across the disability, aged care, health and housing sectors, and all levels of government to meet the 2025 target. However, in some locations, such as rural areas, this is likely to be particularly challenging and could inadvertently lead to increased isolation unless it is done with great care.

Within the Australian Government, joint actions to achieve targeted reductions are overseen by the YPIRAC Joint Agency Taskforce, which includes representatives from the DSS, Department of Health and Aged Care, and the NDIA.

3.7.2. Disability is a predictable outcome of old age

As the Productivity Commission noted in its 2011 report, whether someone has lived most of their life with or without a disability, 'disability is a predictable outcome of old age,' and both the aged care system and the NDIS should be designed so people receive the support that is most appropriate for their needs.[456]

As people age, the likelihood they develop disability or their existing disability may deteriorate, which impacts the type of support people need to live independently as possible.

Ageing is associated with increased frailty, a greater chance of functional impacts from chronic health conditions, and a greater incidence of declines in vision, hearing, and cognition.[457] This means almost half of all people over the age of 65 have a disability. As of 2018, this represents around 2 million people or around 44.5 per cent of all people with a disability.[458] In addition, the number of older people with disability is expected to rise as the aged population grows.[459]

Figure 16: Disability prevalence rates by age and sex [460]

Legend:
- Males with disability (%)
- Females with disability (%)
- Males with profound or severe limitation (%)
- Females with profound or severe limitation (%)
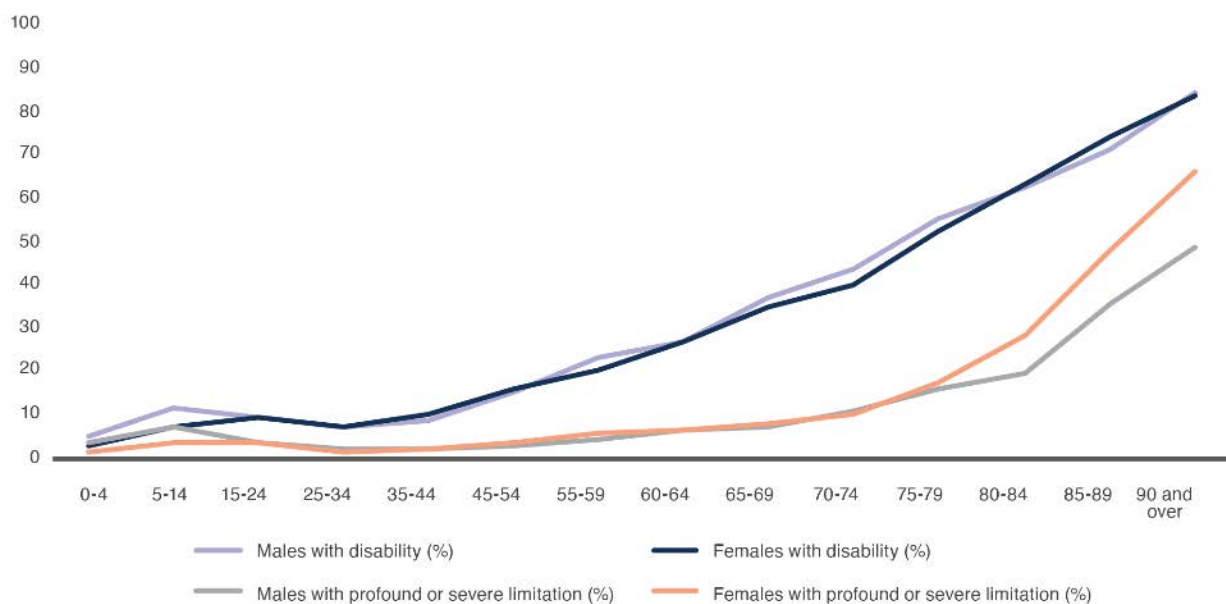
While some disabilities are associated with age, trying to determine whether disability is age related or not can be difficult, if not impossible. It is for this reason that the Productivity Commission and Australian governments decided that an age-based cut off for the NDIS would be the simplest to administer and the most equitable approach. Frailty associated with ageing may affect some people earlier than the age of 65. This may include, for example, early onset dementia, which is also more common in people with Down syndrome.[461] In addition, some neurological conditions such as Parkinson's disease are age-related, but not solely caused by ageing.[462]

The UNCRPD does not distinguish between disabilities acquired early in life and those associated with ageing.[463] Both the NDIS and the aged care system are based on commitments to human rights, and the Australian Government has committed to further enshrining these rights as part of the new Aged Care Act.[464]

3.7.3. Differences between the NDIS and aged care system for older people with disability are driving concerns of inequity and NDIS sustainability

People with disability receive different levels of support in the NDIS and aged care, creating a strong incentive for participants to remain in the NDIS as opposed to choosing to enter residential aged care where this is appropriate for their needs.

When the Productivity Commission held their 2011 inquiry into Disability Care and Support, disability support was fragmented and underfunded. Ten years on after the implementation of the NDIS, there is generally greater support available to people with disability in the NDIS than available through aged care. The reverse was true before the NDIS was introduced. However, in some specific cases aged care supports may benefit NDIS participants who generally do not have access to them.

Inequity has been raised as a key issue of concern by several submissions.[465] Inequity can relate to both the appropriateness of the supports provided, and to the overall level of support one system provides compared to the other.

For instance, the aged care system prioritises support for an older person's clinical care needs, including greater nursing support, particularly in residential aged care.[466] We have also heard that the current stock of specialist disability accommodation used by participants receiving Supported Independent Living (SIL) supports, may be not fit for purpose as participants age.[467] This may mean that residential aged care in particular can provide a service offer that better meets the needs of many people with disability as they age.

However, the NDIS generally provides greater levels of support for people to be active in their community, and as the Aged Care Royal Commission noted, there is more funding per person in the NDIS when compared to the aged care system.[468] In addition, some goods and services are funded by the NDIS, but not by the aged care system, such as more sophisticated assistive technology or other goods and equipment or home modifications to meet support needs and enable people to remain living independently at home.[469]

Overall, this means that older NDIS participants can generally access more support services and can exercise greater choice and control than the same person in the aged care system. Some comparative data is provided in Figure 17. It has not been adjusted for age, disability type or severity. As a result, the comparisons should be seen as indicative.

Figure 17: Average funding levels across the NDIS, Disability Support for Older Australians (DSOA), and aged care for people over 65

Type of care	Average payments per person per year provided by Government, FY 2022-23[470]
Commonwealth Home Support Programme	$3,000
Home Care Package	$22,000
NDIS over-65: non-SIL	$74,800
Disability Support for Older Australians (DSOA): non-SIL	$81,600
Residential Aged Care	$85,000
NDIS over-65: all	$106,500
NDIS over-65: dual participants (NDIS and RAC)	$150,000
DSOA: all	$215,000
DSOA: SIL	$305,000
NDIS over-65: SIL	$362,200

In addition to the generally higher degree of support available in the NDIS, the aged care system subsidises services, subject to caps and means testing. On the other hand, the NDIS pays all reasonable and necessary costs, without means testing, co-payments or financial contribution from participants, as determined through planning sessions administered by the NDIA.[471]

Furthermore, there is a lack of information available to participants on what moving from the NDIS to aged care would mean for them and a lack of assistance to move. This means people are less able to make fully informed choices about where the best supports are available.

NDIS access rates for people over 55 indicate higher numbers of applicants as people age towards 65 but decreasing rates of eligibility.

Figure 18: NDIS access decisions, age 55+[472]
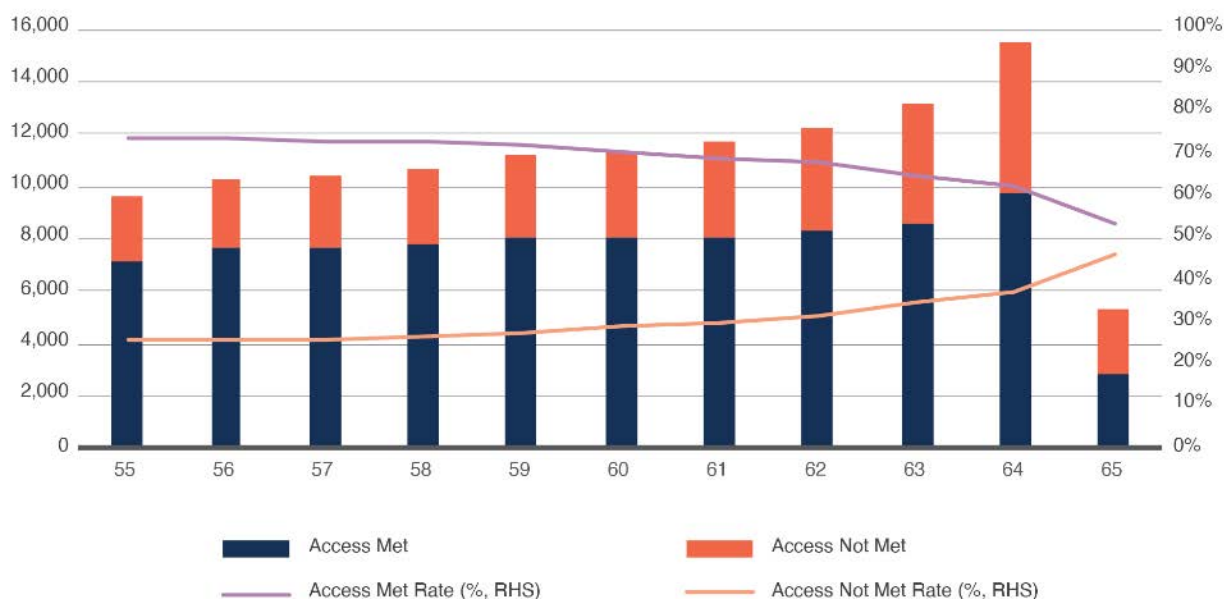
After adulthood, application rates steadily increase as a person gets older, and rise fastest in the years after 60. Across the history of the scheme to June 2023, 15,500 people aged 64 received an access decision (access met or not met), which was 18 per cent more than those aged 63. This increase in the number of access decisions from age 63 to 64 is more than the average increase from 55 to 64, which was 5.2 per cent, as shown in Figure 18.[473] Comparing this to the growth rate of disability among all adults, which averages around 5 per cent for each additional year between 64 and 69, NDIS access decisions nearing age 65 are higher than would be expected.[474]

For those unable to access the NDIS due to age, the disparity between the NDIS and the aged care system both appears unfair, as several submissions have raised,[475] and creates incentives that contributes to higher-than-expected NDIS growth.

As at 30 June 2023, there were 27,500 NDIS participants (or 4.5 per cent) over 65, but this is expected to grow to around 75,300 (or 7.4 per cent) by 30 June 2032[476]. NDIS funding for those aged 65 and over is expected to increase from 7.6 per cent ($2.7 billion per year) of the scheme in 2022-23, to 12.9 per cent ($11.431 billion per year) in 2031-32[477]. This is the fastest funding growth rate of any age group in the NDIS, at around 18.1 per cent each year over this period, as shown in Figure 19.

Figure 19: Total payments and growth rate by age group for NDIS participants[478]
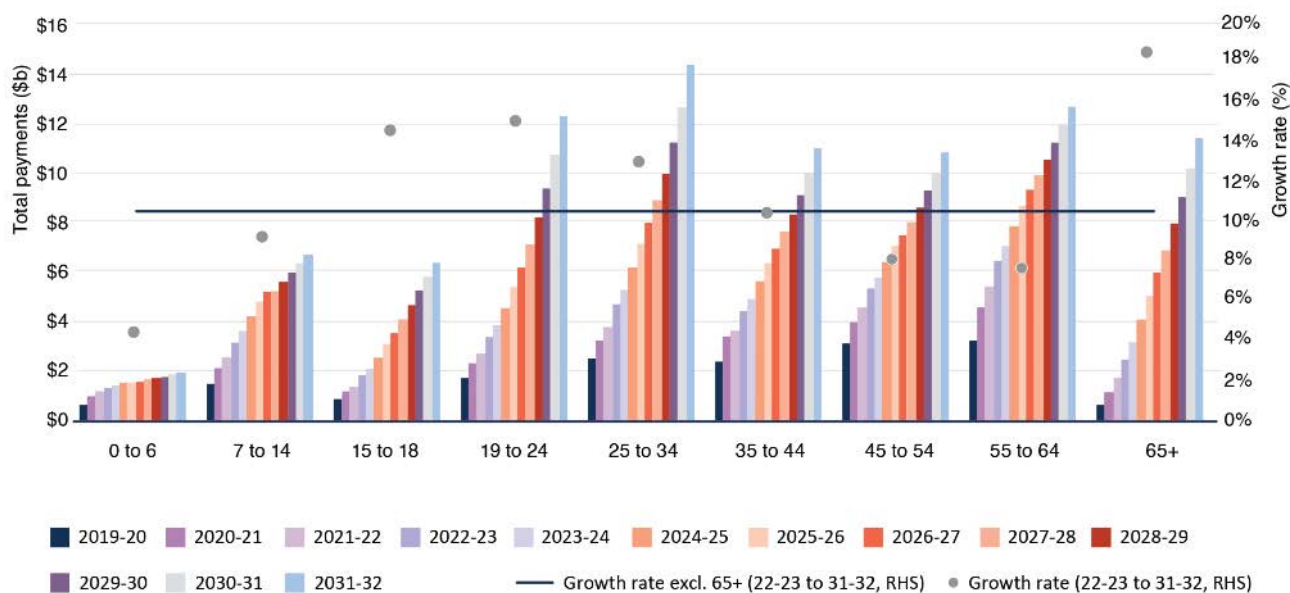
This is driven by the number of people expected to age into this group (noting that this group would be expected to grow at a somewhat faster extent as people age within the scheme), combined with low exit rates to aged care, and a high level of funding per person. As of June 2023, annualised average funding per person aged 65 and over in the NDIS was the second highest of any age group at $134,600, compared to the scheme average of $74,900. [479]

The proportion of people using SIL is also a key contributor to overall costs. As at 30 June 2023, the number of participants who were aged 65 or over with a SIL plan was around 3,100, or 11.4 per cent of all participants aged over 65.[480] As of 30 June 2023, this group had an average annualised funding of $383,200.[481] In 2022-23 these participants spent $1.0 billion on supports. This is expected to increase to 6,100 participants by 30 June 2023 and spend $3.7 billion in 2031-32.[482]

Scheme costs were always expected to rise as people with disability aged within the system, until it reached maturity. However, some people have claimed that the original intentions of the Productivity Commission have not held up, and scheme costs are growing much faster than expected as a result.[483]

3.7.4. The NDIS and aged care system can work better together and reform should align with principles that improve efficiency, effectiveness, and ensure people get the support that best meets their needs

In the current state, incentives appear to reduce the likelihood of NDIS participants aged 65 taking up supports offered by the aged care system, even when the aged care system may provide supports that better meet their needs.

To get the best outcomes for people with disability as they age, we know that the aged care system and the disability support system need to work better together. We want reforms that will ensure:

- Both the NDIS and the aged care system should uphold human rights as their core values and align with the UNCRPD
- The NDIS should remain primarily designed for disability acquired earlier in life (before the age of 65), and the aged care system for ageing needs and associated disability acquired later in life, after the age of 65
- NDIS participants aged 65 and over should be provided with the information and support they need to make informed choices about which supports and service system are most appropriate for their needs
- The two systems - NDIS and aged care – should work together more closely where it is possible and practical to do so, to enable NDIS participants to access the most appropriate, sustainable, and seamless mix of NDIS and aged care supports and services when they are aged 65 and older and aged 50 and older for First Nations Australians and those who are homeless or at risk of homelessness.

Reforms are currently underway, including aged care reforms undertaken and flowing from the Aged Care Royal Commission, the Care and Support Economy Taskforce, and the Aged Care Taskforce. These processes should enable greater collaboration and more consistent regulation between the NDIS and the aged care system over time, lowering the cost of interacting with and moving between either system.

In addition, following recommendations from the Aged Care Royal Commission, the aged care system is currently undergoing a reform process to improve its support and service offerings, including for people with disability (Support at Home Program).[484]

Box 9: Aged care reforms

Since the Royal Commission into Aged Care Quality and Safety released its final report in 2021, the Australian Government has committed to and has undertaken several significant reforms to implement the Royal Commission's recommendations.[485] This includes:

- Improvements to residential aged care, such as a more equitable funding model better aligned to resident needs, star ratings to drive quality improvements and help people make more informed choices, increased direct care (personal care and care by enrolled and Registered nurses) and 24/7 registered nurse care
- Improvements to in-home care involving better assessment and better targeted funding, better access to short term and restorative care, and better access to assistive technology and home modifications
- A new enforceable code of conduct, improved governance arrangements, and increased financial and prudential oversight for people's accommodation deposits and bonds

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- Improvements to incident management and prevention by extension of the Serious Incident Response Scheme, revisions to restricted practice arrangements
- Expanded functionality of the Independent Health and Aged Care Pricing Authority to include pricing advice to Government on aged and general health care

A new Aged Care Act that creates an aged care system that places older people and their rights at the centre and supports choices about their care.

There remains, however, additional work to be done to improve the way the NDIS and the aged care system work together to improve outcomes for older people with disability.

3.7.5. We know what the first steps should be to improve the interface between aged care and the NDIS

Reform must begin with improved data and evidence. A strong evidence base is needed to understand the support needs of both current and new NDIS participants and people with disability aged 65 and over. This will build a more comprehensive and comparable understanding of how supports needs are assessed and provided for in the NDIS and the aged care system.

We understand that such analysis is being undertaken in a joint DSS-NDIA research project focussed on ageing in the scheme, with input from Department of Health and Aged Care and the Department of Veterans' Affairs. As this will usefully inform future changes in this sector, we recommend this analysis on how needs can be measured and compared consistently across the NDIS and aged care be prioritised.

Once this mapping is in place, the NDIS and the aged care system should introduce joint processes for participants aged 65, including joint assessments, to ensure a comprehensive understanding of support needs. This will help inform participant's decisions about their future support needs and enable a seamless transition from the NDIS supports to aged care supports when relevant.

As per the principles above, this process should always ensure that a person makes an informed choice about where they receive supports, and which system will best meet their needs.

3.7.6. The NDIS and the aged care system should allow for NDIS participants to access supports in both systems

However, even if support needs for older participants are better understood, incentives will remain for NDIS supports to be used instead of aged care supports, even when aged care supports better meet someone's needs.

The Panel considered a range of options based on a wide range of submissions and feedback suggesting solutions to address issues with the aged care interface. Figure 20 outlines options that were considered, but not recommended.

Figure 20: Options considered to improve the interface between the NDIS and aged care

Options not recommended	Review view
Trigger movement from the NDIS to aged care at a certain age or milestone.	While this would have a significant impact on scheme cost growth, it would do so at significant negative outcomes for participants. As we have already noted, it is a very different experience to have a lifelong disability compared to acquiring a disability later in life. For a number of participants over 65, the supports that the NDIS provides would not be fully replaced by the aged care system in its current state. This would create a change in care levels that could risk real harm for some older participants. We view this as an inappropriate response Government should not consider.
Remove age 65 entry restrictions for the NDIS.	While this may theoretically improve equity, it would likely increase NDIS cost growth significantly, and runs counter to the original design and insurance intentions of the scheme. In addition, the Government has also clearly stated its policy positions that the age 65 boundary for the NDIS should remain, and that no-one under the age of 65 should enter the aged care system.[486]
	We note the issues some people over 65 who suffer a catastrophic injury face, when their injuries are not covered by a no-fault insurance scheme, and recommend implementation of the missing parts of the National Injury Insurance Scheme to fill this gap (see Section 3.9).
Introduce means testing for NDIS participants over the age of 65.	The Productivity Commission originally recommended this option,[487] but it was not introduced when the scheme was originally designed. We recognise this option would be seen by many as a fundamental shift in the way the NDIS is designed. In addition, as most older people in the NDIS are reliant on the Disability Support Pension, it would likely only have a moderate impact on scheme costs.
	We consider this option inequitable and of limited benefit.

Two options, however, were considered in greater detail.

Option 1. Allow dual participation in the NDIS and aged care after the age of 65.

This option would expand the choices older participants have available to meet their aging related needs by allowing them to take up more intensive aged care supports without losing access to the NDIS, as the current settings mandate.

Groups who may already have different access settings should be able to maintain these settings – for example, First Nations people should continue to have the option to be dual participants after age 50.

This option would be actioned by changing section 29(1)(b) of the NDIS Act, which prevents NDIS participants aged 65 and over from accessing significant aged care supports as well as NDIS supports. NDIS eligibility requirements, however, would mean people still need to enter the NDIS before the age of 65.

This should improve outcomes for participants, as certain aged care supports may be more appropriate than NDIS supports for those with ageing related needs (for instance, when someone requires 24/7 nursing support). Concurrently, it may be appropriate for the NDIS to continue providing certain services after a participant moves into the aged care system. A good example

would be a wheelchair with highly customised seating designed to prevent pressure sores. This option would ensure NDIS participants will have the appropriate support they need to age with dignity.

This should also address the sustainability of the NDIS, as SIL would no longer be the default and only option available to NDIS participants as they age.

With dual participation, a NDIS participant would be able to use the service coverage of aged care (such as when it is the best option, or where there may be no available NDIS supports) and the aged care system may have a lower funding cost than supports available in the NDIS. This is especially relevant for home and living supports such as SIL.

Figure 21: How option 1 would work for participants
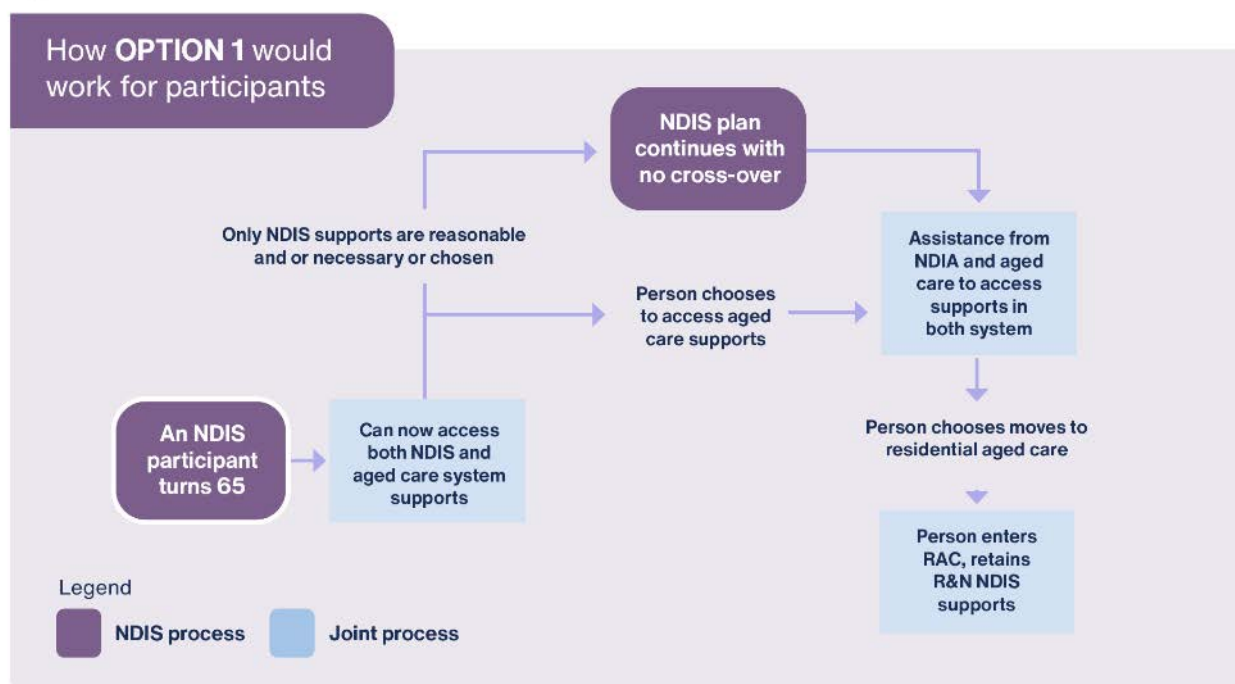
There is a precedent for drawing on support from both the NDIS and the aged care system. As at 31 December 2022, there were over 4,200 people in aged care and the NDIS simultaneously, referred to as dual participants. [488] Half of these dual participants are below 65 (see Box 8) and half over as they entered RAC before turning 65.

The total cost of enabling participants to use NDIS supports while in aged care will depend on reforms to the participant pathway including assessment and budget setting outlined elsewhere in this report (see Chapter 2). Our analysis suggests this would largely be cost-neutral.

In addition, governments should also develop clearer policy, NDIS rules and guidance as necessary to clarify when aged care supports are more appropriately considered the responsibility of the aged care system as part of considering reasonable and necessary NDIS supports, and where complementary NDIS supports should continue to be funded.

Due to its simplicity and fairness, we consider this is a viable option that can be implemented in the immediate future.

Option 2. Limit NDIS package growth after a participant is found eligible for aged care, and allow ongoing specialist NDIS support for those who take up aged care supports

We carefully considered this option that would also increase choice in relation to accessing supports across both systems, but would incentivise participants to take up aged care supports to a greater degree in relation to meeting both their functional support and ageing related needs.

Once participants turned a certain age, such as 65 or 70, and being assessed as eligible for aged care supports, their NDIS package growth would be limited to the size of their plan at assessment plus an additional growth buffer equal to the maximum aged care home support payment (adjusted yearly for the rate of inflation).

That is, participants would be entitled to receive their NDIS supports and the additional equivalent value of home-based aged care supports in the NDIS after 65. In addition, to address any potential gaps, NDIS participants who moved to use aged care supports would retain any assistive technology and specialist disability supports if the aged care system does not provide these supports.

For example, a 70-year-old participant with a $100,000 per year plan value would undertake a joint assessment with the NDIA and Department of Health and Aged Care. If this joint assessment found they are eligible for aged care, then their future NDIS plan funding would be limited to $100,000 per year plus inflation plus the maximum Home Care Package payment, currently around $59,600 per year.[489] If, over time, their plan reaches $159,600, plus any inflation, then they would either need to reallocate funding in their plan to those supports they need most or seek additional support in the aged care system. If for example, they moved into residential aged care, but in their NDIS plan they had $10,000 worth of assistive technology that the aged care system didn't yet fund, they would take this with them.

Two further points are noteworthy;

- First, the original package of $100,000 will almost certainly include an amount for social and community participation and as people age they are likely to want to spend more time at home. Therefore they could shift funds within their core budget to provide more support for activities of daily living.
- Second, in an environment where it is always very challenging to ensure equity between service systems, this approach would align with the community's willingness to support older Australians, as measured by the maximum Home Care package, and so align with community norms and support for ageing in place after the age of 65.

Figure 22: How option 2 would work for participants
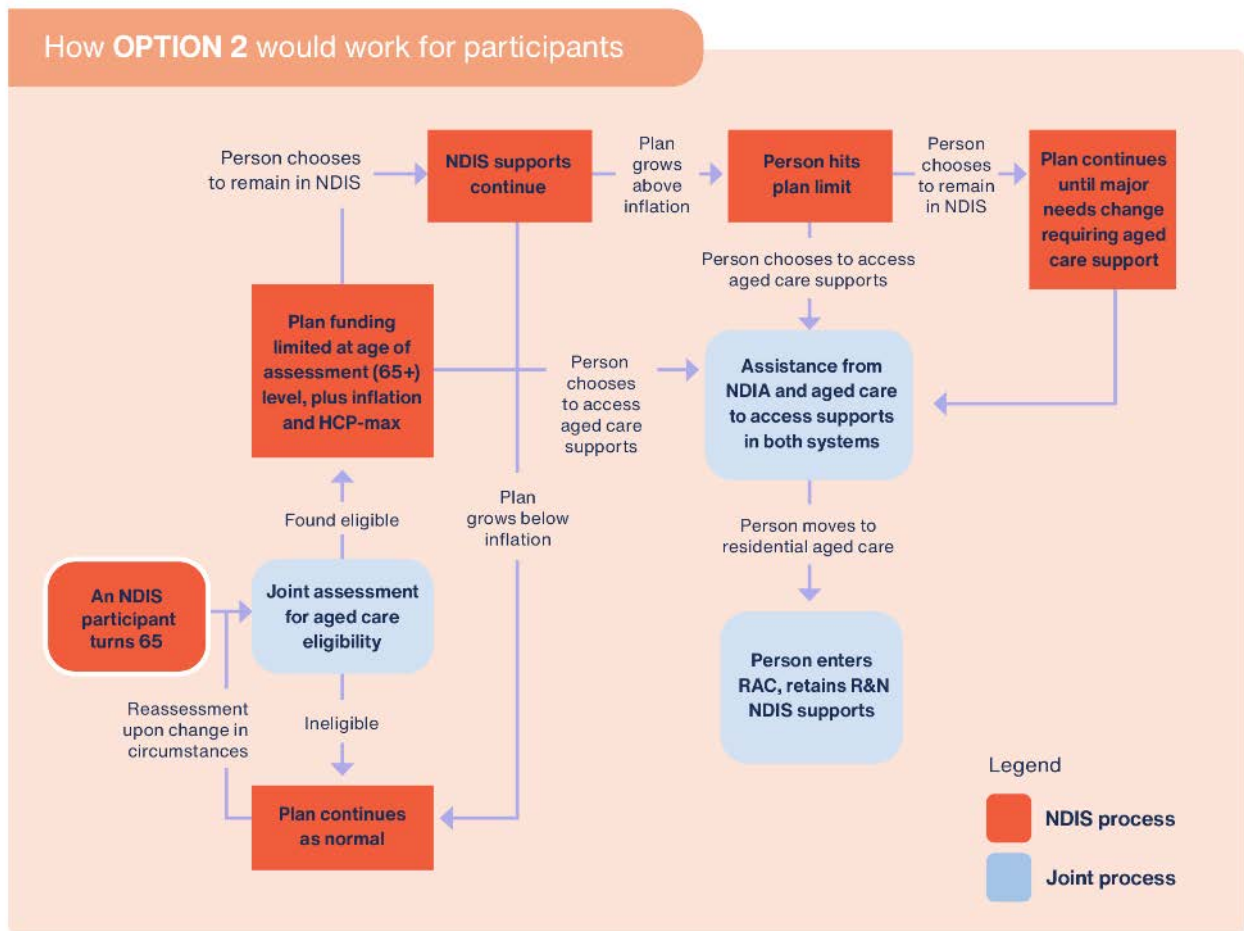
This option would be complex to administer, though the complexity would be borne largely by the NDIA and aged care system. From the perspective of participants this approach could raise several concerns that would need to be mitigated:

Figure 23: Possible concerns from participants and mitigations for option 2

Concern	Mitigation
Could someone hit the provision limit and be forced into aged care?	Due to the joint assessment process, only those found eligible for aged care (i.e. aged care is suitable for their needs) would be subject to the limit.
	Once a participant's assessed funding needs reached the limit, they would not be forced to move. If they wish to use only NDIS supports, they can reallocate funding to prioritise certain supports within their budget.
What if aged care doesn't provide adequate disability support?	As noted above, participants would only be subject to the limit if aged care is assessed as a suitable option. Ongoing aged care reforms are underway to improve the standard of care and the service offering for people with a broader range of disability needs.
	In addition, participants would be able to retain assistive technology and specialist support from the NDIS if a gap exists.
How quickly would people hit the limit?	Modelling suggests that those with higher plans would hit the limit faster, but only those found eligible would be subject to it. For most NDIS participants, there would be around a 20 per cent chance on average of hitting the limit within 10 years of being assessed.
	If the maximum aged care home care packages increase during the current aged care system reviews, this would mean it would take participants longer on average to hit the limit.

This option would have significant long to medium term impacts on scheme sustainability. It is likely to reduce NDIS costs by $0.9 to $2.3 billion per year within ten years of implementation, depending on settings, with costs reductions growing cumulatively each year.[490] Noting aged care costs would increase, there should still be a large systemic cost reduction due to the difference between NDIS and aged care support costs.

However, due to the complexity of this reform and the potential impact on participants, we did not consider this a feasible or appropriate option.

Path forward

In consideration of the options we have explored, we recommend option 1 – enabling dual participation in the NDIS and the aged care system – as the most practical in the near term, due to its fairness and simplicity.

3.7.7. The Disability Support for Older Australians program and the NDIS should be aligned

To provide support for older people with disability who were not eligible for the NDIS when the NDIS commenced in their region, the government created the Commonwealth Continuity of Support (CoS) Programme. CoS was replaced by the Disability Support for Older Australians (DSOA) Program on 1 July 2021.[491]

DSOA is closed to new entrants given transition has been completed. As of June 2023, DSOA is estimated to service around 2,050 people and cost around $435 million per year, with overall costs and the number of people supported reducing year on year.[492] There is broad equivalence of costs between the NDIS and DSOA, with around 1,150 SIL clients in DSOA receiving funding of on average $305,000, and the remaining clients receiving funding of on average $81,600.[493]

DSOA has also implemented ways to manage the transition to aged care and sustainability:

- If a DSOA participant's funding needs increase, a Needs Assessment is required, which can recommend an aged care assessment must be undertaken
- If the aged care assessment finds a DSOA participant is eligible for aged care (i.e. the aged care system is appropriate), then DSOA funding is frozen at their current level
- DSOA participants have a 'service coordinator', who in the above circumstances will help them transition to aged care if the participant chooses to.[494]

DSOA is largely aligned to the NDIS. However, some areas, including SDA funding and aged care transition, work differently for those in DSOA or the NDIS. Changes to the NDIS would mean DSOA would have to change or misalignment would increase.

To improve the consistency of support and funding for those in the DSOA and in the NDIS including the recommendation to work with residents in legacy SDA and states and territories to phase out legacy SDA (see Action 9.8), we recommend that DSOA cease to operate, and DSOA participants become NDIS participants.

The cost of shifting DSOA participants into the NDIS will be offset by wrapping up DSOA. The system cost of merging DSOA is expected to be a net cost of around 10 to 20 per cent of DSOA costs, as some DSOA participants may experience an uplift in support and to account for transition costs.[495] It should be noted that because DSOA supports a closed cohort, these net additional costs would not be a material medium to long-term cost for the scheme.

3.7.8. Action & Implementation Details

Action 2.11: The Australian Government should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary

The National Disability Insurance Agency (NDIA) and the aged care system should institute a new joint model of cooperation, including a shared assessment model. This should ensure greater choice for older participants. This will require the Australian Government to change the clause in section 29(1)(b) of the *National Disability Insurance Scheme Act 2013* and allow participants over the age of 65 to have expanded access to aged care system supports, including residential aged care, while remaining eligible for complementary NDIS supports.

Implementation detail

The NDIA, Department of Social Services, and Department of Health and Aged Care should:

- Undertake research to better understand and identify changes in a person's support needs as they age, and map these changes to which supports in which system are best placed to *support these needs (for example, 24/7 nursing needs)*

- Establish a joint process between the NDIS and aged care system to assist participants over 65 to take up new aged care supports in addition to NDIS supports as seamlessly as possible, when appropriate and when a participant has made an informed choice to do so
- Update legislation, rules, and guidance to clarify when aged care supports are reasonable and necessary, and that more intensive NDIS supports that may exist as an alternative should only be used when aged care supports are less appropriate.

Action 2.12: The Australian Government should implement legislative or process change to allow access to the NDIS for Disability Support for Older Australians program participants

Once all remaining Disability *Support for Older Australians (DSOA) participants have moved to the NDIS or aged care system, DSOA should cease.*

Implementation detail

Following the needs mapping and joint process recommended in action 2.11, the Australian Government should:

- Update legislation as needed to allow for those people currently accessing DSOA to move into the NDIS
- Support current DSOA participants to transition across to the NDIS or aged care system, based on informed choice as to what is most appropriate to their circumstances.

3.8. Child development systems can be more effective in identifying developmental concerns and disability

Children with emerging developmental concerns and disability need to be identified as early as possible to ensure timely support can be provided. Gaps in development open early and widen progressively without early intervention.[496]

> *"The most efficient way to support all developmentally vulnerable children is to identify them and commence supports within their first 1000 days… Regardless of where they live, all children should have access to a minimum number of maternal and child health (MCH) visits, where their development (social-emotional, language and physical development) and the primary caregiver's wellbeing are monitored throughout the first 3 years of life." – Olga Tennison Autism Research Centre [497]*

Many children with developmental concerns and disability are not being identified as early as possible. This means their needs are not being met as soon as they should be. By example, while the average age of entry for children accessing the NDIS has improved, it remains well past the critical 1,000 day period.[498] Going forward, when foundational supports are in place, accessing these services will be the first critical step, but access to the NDIS, where needed, will still need to be timely and so will require a smooth access process.

Figure 24: Average age of entry for children aged under 9 entering the NDIS[499]

Financial Year

Children and families from First Nations or culturally and linguistically diverse backgrounds also face barriers to accessing health and disability supports.[500] This means that some children and their families are having to wait until later in life, when they reach school or in the worst-case scenario upon involvement with the justice system, to have disability identified and receive supports.[501]

> *"Parents of children with disability in particular, expressed fear of having their children removed if they are identified as having disability… When First Nations individuals and families had accessed diagnostic services, they also described experiencing medical dismissiveness or mis-diagnoses, which prevented them from accessing appropriate supports and services. In a number of cases for instance, families spoke about their children being mis-diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) – instead of Autism or Foetal Alcohol Spectrum Disorder (FASD) – which is not eligible for funding under the NDIS." – First Peoples Disability Network[502]*

We heard of organisations responding to this challenge with service models that provide culturally responsive diagnosis and support.[503]

There are two main components to developmental checks.[504] First, developmental monitoring is a process to observe how children are growing and changing over time. Families and caregivers, with

the right tools and information, are often best placed to do this monitoring as they spend the majority of time with their children. This involves observing how children are growing and changing over time and monitoring milestones in play, learning, communication behaviour and movement. However, doing this effectively can be very challenging for parents when monitoring the progress of their first child, as they do not have first-hand experience of normal development.

Second, developmental screening is a closer look at a child's development in areas of language, movement, thinking, behaviour, and emotions. This is usually undertaken by a professional with expertise in child development. It may involve brief assessment of the child or the caregiver completing a questionnaire or formal evidence based checklists.

All states and territories have established maternal and child health services for conducting child health and development checks across the ages and stages in the early years. However, the approach for these checks varies across jurisdictions.[505] See Figure 25 for further detail on the frequency of recommended and offered child health and development checks across different jurisdictions.

A stark example of the differences is that the maximum number of total recommended checks is in the Northern Territory with 14 and the minimum is in South Australia and Western Australia with six. This is a difference of more than double the number of recommended checks. [506]

Considering the timing of the checks also reveals differences across jurisdictions. In the first 12 months, both Victoria and the Northern Territory have seven recommended checks which is the most across the jurisdictions. Whereas, South Australia, Western Australia and the Australian Government recommend four checks in the first 12 months. Both Western Australia and Tasmania don't have a check at 18 months, which is when motor, communication and language delays can be more evident. Signs of autism are also frequently identified at the 18-month assessment. [507]

By either measure there is a significant difference in approach across jurisdictions.

It's also important to recognise that this represents the maximum number of offered checks. Utilisation of these checks is far lower which means the number of checks completed is well below the maximum. [508] [509] This creates a scenario where a jurisdiction with a lower number of checks but with higher utilisation of those checks can be practically more effective in identifying need than a jurisdiction with a higher number of checks with lower utilisation.

There are also significant barriers for many families to access mainstream services in the early years. These include groups who find some mainstream services inaccessible or not culturally safe. This means there is not a single service system who has full contact with all children to assist with developmental checks. Effective coverage requires a more holistic and tailored approach across systems.

A lack of consistently reported data across jurisdictions also makes it challenging to easily understand the uptake and usage of these health and development checks, as well as more targeted services. This creates a significant gap in understanding the coverage and outcomes of

developmental checks across Australia and how they link families to early intervention services. It ultimately means there isn't enough data on need to better inform policy and program responses.

Figure 25: Child health and development checks by jurisdiction (note we have attempted to group checks together by timing to make visual comparison easier). Hv = hospital visit. Doc = doctor.[510]

National	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Checks <12 months								
Birth (hv) 1-4 weeks	Birth (hv) 1-4 weeks	Birth (hv) 2 weeks 4 weeks	0-4 weeks	1-4 weeks (hv) 2 weeks (doc)	0-2 weeks	2 weeks 4 weeks	0-10 days (hv) 4 weeks	1-4 weeks
6-8 weeks	6-8 weeks	8 weeks	8 weeks	6 weeks (doc)	8 weeks	8 weeks	6-8 weeks	6-8 weeks
		4 months	4 months		4 months		4 months	4 months
6-9 months	6 months		6 months	6-9 months		6 months	6 months	6 months
		8 months					9 months	
Checks >12 months								
	12 months	12 months	12 months		12 months	12 months	12 months	12 months
18 months	18 months	18 months	18 months	18-24 months			18 months	18 months
2 years	2 years	2 years	2.5-3.5 years		2 years	2 years	2 years 2.5 years	2 years
3 years	3 years	3.5 years		3 years			3 years 3.5 years	3 years
4 years	4 years		4.5 years		4 years	4 years	4 years 4.5 years	4 years

3.8.1.   Developmental checks must occur in multiple settings where children and families interact

Implementing a holistic and joined up continuum of supports for children with disability and developmental concerns should be an urgent priority for all governments. This is a key recommendation of the Review. Section 2.9 provides more detail on the proposed continuum of support for children.

Early identification of developmental concerns and disability is a key part of delivering this continuum. Identifying children with developmental concerns and disability early can enable more timely intervention from mainstream, foundational and/or NDIS supports.

Acknowledging the evidence does not support a 'best practice' approach to the frequency and number of universal health and family checks, we believe that attention is needed to promote greater consistency and accessibility across jurisdictions, particularly across the first 1,000 days until a child's second birthday.[511]

To deliver on this, there needs to be a refreshed, consistent national framework and approach for developmental checks across jurisdictions, including a minimum level of developmental monitoring over children's ages and stages. This should consider embedding contemporary tools and approaches (see Box 10). It should also include a national approach to minimum data requirements to more accurately understand usage of developmental checks.

To increase accessibility and uptake, the approach also requires checks to be delivered across multiple settings that support young children and their families. This would be delivered through an expansion of universally available child development checks. This should be implemented opportunistically by multiple mainstream services who work with children by professionals trained to understand child development. This means checks are being delivered across maternal child health services, integrated child and family centres, general practice and other health services, and early childhood education and care. The new framework and approach should also account for additional efforts or tailored approaches to reach families who may find it more difficult or culturally unsafe to engage.

We have heard that the priority is to ensure that checks occur widely, early and often to ensure all children are reached. The important principle is connecting with children and families where they are and where they are most likely to feel safe and supported. This will require greater information and capacity building resources to be supplied to mainstream services undertaking these checks. We have also heard about the importance of seeking and responding, rather than seeking and referring. The key need is both to seek and respond in a timely manner and act appropriately.

Similarly, consideration should be given to ways to inform and support parents understanding of their role in developmental monitoring.

Box 10: Indicative framework to guide a more consistent approach

This approach should be guided by a refreshed framework for developmental monitoring and screening across the first five years of life. The purpose of the framework is to establish the key direction and components of the approach across jurisdictions.

This should be developed with states and territories and a wide range of experts in child development, early intervention, and developmental monitoring and screening.

The framework should include:

- Agreed principles to guide the approach

- Agreement for the content and timing of developmental checks
- Strategies to achieve widespread coverage of child developmental checks by supplementing maternal and child health and development checks with checks in general practice, other health services such as Aboriginal Controlled Community Health Organisations, GPs and Early Childhood Education and Care (by professionals trained to understand child development)
- Agreement on the types of screening tools and when they should be used. This should specifically consider opportunities to embed the culturally tailored Ages and Stages Trak tool for Aboriginal and Torres Strait Islander children
- An approach to providing information and capacity building resources approaches to support mainstream services who work with children to opportunistically undertake checks
- An approach to providing information and capacity building resources to support families to understand developmental checks, including their role
- Minimum data collection requirements to measure the availability and take up rates of checks. As well as an approach to transparently reporting this information.

The case studies below highlight some of the different methods and tools that can be used to engage families in early, culturally appropriate developmental monitoring.

Case Study 4: Early, culturally appropriate developmental monitoring methods and tools

The Social Attention and Communication Surveillance (SACS) tool for early autism detection[512]

What: Social Attention and Communication Surveillance-Revised (SACS-R) and SACS-Preschool tools are developmental surveillance tools to assist professionals to identify children who are highly likely to be autistic. The method has also been converted into a free mobile app called ASDetect that guides parents through age-appropriate assessments, using videos of autistic and non-autistic children to illustrate questions about social communication milestones. Families can receive a result of low or high likelihood of autism and a comprehensive email that can be taken to their doctor for further discussion.

Where: The tool can be used in routine consultations with maternal and child health nurses. The app is available for use at any time.

Why: Research shows the tool has very high diagnostic accuracy for early autism detection. This facilitates child and family access to time critical early intervention supports.

When: Routine checkups with maternal child health nurses. The app is suitable for children aged between 11 and 30 months.

Watch Me Grow Electronic Platform (WMG-E)[513]

What: The WMG-E is a free online platform where child development can be monitored by families. It can guide families towards more detailed assessments where need is identified.

Where: Use of the WMG-E has been trialed in primary care (general practice) and early childhood education and care settings (playgroups). During COVID-19 it was also made available to families at homes and communities through trusted providers.

Why: Uptake of child development screening is patchy. Using opportunistic contacts to involve families in developmental monitoring can improve uptake, engagement and outcomes.

When: Opportunistic contacts with children and families such as visits to the doctor, or playgroups.

Ages & Stages Questionnaires – Talking about Raising Aboriginal Kids (ASQ-TRAK) [514]

What: Developmental screening tool for observing and monitoring the development of Aboriginal and Torres Strait Islander kids. It is based on the ASQ tool, but has been modified to be culturally appropriate, shorter, and to use plain language and illustrations. It takes a strengths based approach and aims to catch delays early.

Where: It is designed to be used by early childhood educators and health professionals. It is administered by interview, making families a part of the process and teaching them about child development.

Why: To facilitate equitable access to child development support for Aboriginal and Torres Strait Islander children.

When: It is suitable for children aged between 2 months and 5.5 years.

We also saw first-hand examples. On Angurugu (a community located on Groote Eylandt in the Northern Territory), we met the Connected Beginnings team who were delivering ASQ-Trak screening in their community. Local Anindilyakwa women were employed to administer ASQ-Trak screening and were working to connect with children and families living in very remote locations. The Connected Beginnings team estimated that they had reached approximately 80 per cent of the children in the community. We also heard directly from one of the employees of the Connected Beginnings team how she enjoyed her role in keeping the next generation of Anindilyakwa children strong.[515]

3.8.2.   Action & Implementation Details

Action 2.13: All Australian governments should agree as a matter of priority to expand universally available child development checks, to ensure the early identification of children with developmental concerns and disability and enable early intervention.

This approach should build on existing good practice of maternal and child health services in states and territories and internationally for regular health and development checks for young

children. It should be implemented by mainstream services working with children including maternal child health, early childhood education and care, and general practice. This aims to ensure that developmental concerns and disability are consistently identified early across all jurisdictions. There should also be a national approach to minimum data requirements. This should mean needs are met earlier and greater data on need is available to inform the design of future supports.

Implementation detail:

The Australian Government and State and Territory governments should agree to expand universally available child development checks. This should be:

- guided by a refreshed framework for developmental monitoring and screening across the first five years of life (described above). This should be developed with states and territories and a wide range of experts in child development, early intervention, and developmental monitoring and screening.

As part of agreeing the overarching approach, the Australian Government and State and Territory governments should agree to improvements to data collection, measurement and reporting approaches. At a minimum, this should include:

- The Productivity Commission Report on Government Services expanding the Developmental Health Checks dataset to include indicators relating to child developmental monitoring and screening
- The Department of Health and Ageing collecting data on health assessments undertaken in primary health care for children (to allow this to be provided to the Productivity Commission).

3.9. The National Injury Insurance Scheme was never fully implemented and the interface between the NDIS and compensation schemes can be unclear, creating support gaps

There are gaps in care and support for some people who suffer catastrophic injuries that result in disability, depending on how the injury occurred. The presence of these gaps can result in some people getting a lower standard of support or going without. Both can increase pressure on the NDIS.

Some gaps could be covered by a fully implemented National Injury Insurance Scheme (NIIS). The Productivity Commission recommended the creation of a NIIS to sit alongside the NDIS. However, the NIIS has only been implemented in part. Motor vehicle and workplace accidents coverage is in place, but the medical and general accidents streams of the NIIS remain key gaps. Filling these gaps would improve NDIS sustainability and outcomes for all people who may suffer a catastrophic injury at any stage during the course of their lives, including those who are catastrophically injured when they are aged over 65.

In addition, the arrangements between the NDIS and existing compensation schemes can be improved. This would ensure that people receive the full compensation they are entitled to, while minimising any overlap with the NDIS and the stresses and costs this may result in.

3.9.1. People who suffer catastrophic accidents that result in disability face gaps in care and support

When someone suffers a catastrophic injury that results in permanent disability, it has been described as a 'cruel lottery' as to whether they will get the care and support they need, due to the patchwork of schemes that currently exist.[516] Some will be covered by existing compensation schemes, others will enter the NDIS where they may get some but not all the support they need, and some will be left to pay for their own supports or rely on mainstream services.

Compensation schemes here refer to payments for supports outside of the NDIS for losses or injury. These can include motor vehicle accident and compulsory third party (CTP) insurance schemes, workers' compensation schemes, medical negligence schemes, general insurance claims covering permanent illness or injury, and legally determined compensation arrangements.

There are in broad terms two types of compensation arrangement: no-fault and fault-based. There are often particular types of 'damages' covered, including: cost of future care, pain and suffering, and loss of future income. Generally, a fault-based arrangement will require someone to prove fault for the injury in a court (for example, someone suing someone else for damages), while a no-fault scheme will not. Fault-based damages can generally still be pursued even if someone has accessed a no-fault scheme.

However, payments for damages may take into account an injured person's access to supports, including supports received through the NDIS. This means that dependent on the circumstances of an injury, the supports a person can receive (and therefore the impact on the NDIS and potential for cost-shifting) can vary significantly.

If, for example, a person suffers a spinal cord injury or an acquired brain injury, the circumstances under which they acquired this injury will determine the level of care and support they receive. If this injury occurs in a car crash, they will likely be covered under the motor vehicle accidents stream of the NIIS, which every state and territory has rolled out.[517]

The NIIS for motor-vehicle accidents provides reasonable and necessary treatment, care and support for those who are eligible, including medical treatment, rehabilitation including 'slow to recover' programs, domestic assistance, aids and appliances, and home and transport modification, regardless of who was at fault.[518]

If, however, this person suffers the same injury on a sporting field, in an assault or domestic violence incident, or through a fall at home, the outlook is much more uncertain. To take the example of domestic violence, as Associate Professor of Law Kylie Burns noted:

> *"Women who suffer injury have historically encountered and continue to suffer barriers to gaining appropriate damages or compensation for their injuries ... Where a*

woman suffers a serious disability as a result of domestic violence, there may be some lifetime care and support (although no economic loss, medical costs or compensation for pain and suffering) available under the NDIS." – Australian Lawyers Alliance[519]

Having the NDIS cover people who would have otherwise used the NIIS puts further cost pressure on the NDIS. In 2017, the Productivity Commission estimated that the lack of a general accidents NIIS would add $193 million per year in 2025-26, and $417 million per year in 2030-31.[520] Estimates indicate the additional cost to the scheme could be $1 billion per year for participants who have joined the scheme up to 30 September 2023, noting this estimate is preliminary.[521] This amount will increase each year as more people with catastrophic injuries join the scheme who would otherwise have been covered under a general accidents NIIS.

Another inequity is people who acquire disability after 65 due to a catastrophic injury. This group cannot access the NDIS due to its age limit, but may not be as well supported through other available settings, such as the aged care system. We have heard from a number of people and organisations who have raised this inequity.[522]

This was not what was originally intended when the NDIS was designed and does not align with the vision of an ecosystem of support for all Australians with disability.

3.9.2.   Implementation of the general accidents stream of the NIIS should be explored

In 2011, the Productivity Commission recommended a NIIS be established alongside the NDIS to solve this issue and address limitations in providing care, support, and other assistance to people of all ages injured in accidents.[523] The NIIS was to provide lifetime care and support on a no-fault basis to individuals who suffer a catastrophic injury resulting in substantial and permanent disability.

The Productivity Commission recommended the NIIS would be separate from the NDIS for several reasons, as it would:

- Reduce the cost of the NDIS
- Create incentives to deter risky behaviour and reduce risks that contribute to accidents
- Cover a broader range of health costs associated with catastrophic injuries, such as acute care and rehabilitation services the NDIS does not cover.[524]

When rolling out the NDIS, the Australian Government and states and territories agreed that:

"All jurisdictions endeavour to agree minimum benchmarks to provide no-fault lifetime care and support for people who are catastrophically injured through workplace accidents, medical accidents, and criminal and general accidents (occurring in the home or community) by commencement of the NDIS full scheme." – Council of Australian Governments[525]

But of the four originally proposed streams of the NIIS, only the motor vehicle and workplace accident streams are established. In June 2017, the Council of Australian Governments (COAG) agreed to not proceed with the medical treatment injuries stream of the NIIS, and to explore

options for a general accidents stream.[526] However, there has been no progress since then to implement the full NIIS.

The general accidents stream of the NIIS was intended to cover injuries that occur outside of work, a vehicle, or a medical setting. This includes injuries that can occur in essentially every other setting: in the home, on the sporting field, or in the course a social activity. We consider this stream the priority, as medical indemnity insurance arrangements are in already in place to largely deal with medical injuries (though issues related to fault-based arrangements continue).[527]

Implementing a general accidents NIIS would provide access to rehabilitation for those who need it. It would bridge the gap for people aged 65 and over who suffer catastrophic injury through a general accident and who are not currently eligible for the existing streams of the NIIS or the NDIS. It would also substantially offset some of the costs borne in the NDIS, as those who are covered by the NIIS would not be reliant on the NDIS for care and support.

Recently, in this context, the concussions and repeated head trauma in contact sports Senate Inquiry recommended a no-fault insurance scheme of this nature for sporting head injuries:

> *"The committee considers that a no-fault accident injury insurance scheme may be the solution to providing adequate care and support for people who participate in sport and who suffer concussions, brain trauma, and any resulting long-term neurodegenerative conditions."- Senate Community Affairs References Committee[528]*

The general accidents stream of the NIIS could fill this role, as well as for other catastrophic injuries. We therefore recommend, consistent with the original Productivity Commission report and updated evidence provided by the NDIA, that the general accidents stream of the NIIS should be implemented.

The Australian Government Treasury coordinated the implementation of the current parts of the NIIS at a national level. States and territories are responsible for legislating, funding and administering the current parts of the NIIS. Aligning with the Productivity Commission's original recommendations, this builds on existing state and territory capabilities and avoids potential constitutional issues for a national scheme.[529] These arrangements should remain for a general accident stream of the NIIS.

Like the NDIS, implementing the NIIS would come with significant challenges. The general accidents stream of the NIIS would be a large and complex scheme in its own right and would need to be set up in such a way that learns from the experience of implementing the NDIS and other NIIS streams.

To ensure a smooth transition, a rigorous exploration of the expected costs and benefits of the NIIS should be undertaken by Australian Government Treasury. This should include consideration of funding sources, which the Productivity Commission recommended be structured as insurance premiums.[530] For example, the Productivity Commission noted the link between alcohol consumption and catastrophic injury, so an increased alcohol tax could be considered.[531] This

report should be published to provide transparency on the viability of the general accidents stream of the NIIS.

To ensure transparency and adequate prioritisation, the implementation of the general accidents stream of the NIIS could be discussed by National Cabinet by the end of 2024, and tasked to the Council on Federal Financial Relations to seek further comebacks annually, as well as being monitored by the Disability Outcomes Council.

3.9.3. There are coordination issues at the interface between the NDIS and compensation schemes

For those people who are able to access a compensation scheme outside the NDIS, interaction with the NDIS is not always smooth or straightforward and can result in poorer outcomes for participants and extra cost and effort for the NDIS.

The NDIS was never meant to replace the supports that other compensation schemes provide.[532] The NDIS can, however, offer complementary supports that a compensation scheme does not provide. As such, around four per cent of NDIS participants as of June 2023 also have supports provided through compensation schemes.[533]

This interface can be complicated and sensitive. It can take a long-time for compensation to be agreed on, especially outside of no-fault schemes in a contested setting like a court. In addition, seeking compensation may be traumatic, requiring people to relive their own injuries and those they love and go through multiple bureaucratic processes.

The health system, rather than the NDIS, is responsible for services such as rehabilitation, and may not offer the full range of supports in the public system someone would generally receive in a compensation arrangement.[534] We have heard this may lead to 'many injured people missing out on the rehabilitation and other supports they need'.[535]

The NDIS Act and the NDIS Rules govern how the NDIA should account for compensation payments and supports funded or provided by other schemes.[536]

The NDIA also provides operational guidance.[537] Some agreements help resolve potential issues, such as the NIIS motor vehicle accident minimum benchmarks, which specify that states and territories must provide a minimum standard of compensation through the NIIS, or else pay for 100 per cent of NDIS costs for those participants who were eligible.[538] The NDIA noted it is unclear whether minimum benchmarks have been enacted in relation to the workplace accident benchmarks, whether benchmarks are enforceable, and how the NDIA could recoup costs where benchmarks are not met.[539]

It can require significant expertise for all involved to know what is in and out for a given compensation agreement and a participant's NDIS plan. Therefore, there is a significant degree of overlap, as the NDIA is providing supports that compensation arrangements also provide for, which the NDIA estimates in 2022-23 increased NDIS costs by around $114 million per year.[540]

For instance, the NDIA has noted that for the existing workplace and motor vehicle NIIS schemes, supports for a NDIS participant who is accessing both need to undergo a detailed line-by-line comparison process, complicated by a lack of consistent language and definitions across schemes.[541]

To resolve this overlap, the NDIA has a branch that deals with cost recovery for duplication and overlap between the responsibilities of the NDIS and of a compensation scheme. While a necessary function, it comes at a cost as participants may become anxious and stressed where an adjustment is required and the NDIA is required to devote capacity to this.

A better way forward would be to avoid these situations occurring, to the extent that this is possible. We recommend a review of the current rules is completed as a priority. In addition, a way to easily identify when someone applying for the NDIS is also accessing or plans to access a compensation scheme would be highly desirable, as it would improve guidance and navigation for people in these circumstances.

3.9.4. Action & Implementation Details

Action 2.14: State and territory governments should commit to and implement the general accidents stream of the National Injury Insurance Scheme

Implementation of the National Injury Insurance Scheme (NIIS) should bridge the gap for people who suffer catastrophic injury through a general accident and are not currently eligible for the existing streams of the NIIS or the NDIS (such as those aged 65 and over) or rely on the NDIS instead of the NIIS.

Implementation detail

The Australian Government Treasury should:

- Publish and present a report to National Cabinet on the feasibility and expected outcomes of implementing the general accidents stream of the NIIS by end 2024.

Each State and Territory government should:

- Release a public position on whether they will, or why they will not, implement a general accidents stream
- Release an implementation plan and report on implementation progress every year, publicly, and to the Council on Federal Financial Relations.

The Disability Outcomes Council should monitor progress in this area and report to National Cabinet.

Action 2.15: The National Disability Insurance Agency and the Department of Social Services, working with state and territory governments and other relevant Commonwealth agencies, should update current arrangements governing the interaction between the NDIS and compensation schemes to reduce overlap and improve participant experiences

Arrangements in the interfaces between the NDIS and existing accident compensation schemes should ensure that supports are not being shifted to the NDIS or vice versa, that overlap is minimised, and that participants eligible for both have certainty on what support is provided and where.

Implementation detail

The National Disability Insurance Agency (NDIA) and Department of Social Services (DSS) should:

- During the upcoming review of the National Disability Insurance Scheme (Supports for Participants—Accounting for Compensation) Rules 2013, provide additional clarity on: Cost recovery determination; methodologies to guide decision making; determination of what is inside and outside the NDIS; how to consider legal costs; and information gathering.

State and territory governments should:

- Establish transparent mechanisms to show minimum benchmarks for the motor-vehicle and workplace accidents streams of the National Injury Insurance Scheme are in place and being met.

NDIA and DSS, working with state and territory governments, should:

- Improve communication and data exchange between existing compensation schemes and the NDIS
- Improve navigation for people seeking to access any of these schemes (see Recommendation 4).
- Ensure that during eligibility assessment for the NDIS and initial planning, participants and the NDIA can identify any potential overlap between NDIS and compensation arrangements.

3.10. Governments should cease the use of in-kind arrangements in the NDIS

3.10.1. In-kind arrangements were only intended to be a transitional arrangement

NDIS in-kind programs are disability-related supports delivered by Australian Government and state and territory governments for NDIS participants. These supports are funded by the NDIS at an agreed average cost per participant and discounted against states and territories' fixed financial contributions to the NDIS.

As outlined as part of full-scheme bilateral agreements, in-kind programs were only ever intended to be a transitional arrangement. Over the trial, transition and early years of full-scheme NDIS, many of the agreed in-kind programs were cashed-out and incorporated into the NDIS. However, two major programs have remained as in-kind, with outstanding transitional issues unresolved. These are Personal Care in Schools (PCIS) and Specialist School Transport (SST).

Despite extensive research and consultation over the years on how these services could operate in line with the principles of the NDIS, governments have been unable to come to an agreed position. This has led to extending in-kind arrangements for SST and PCIS to the end of 2024 to allow for continuity of support and time for Disability Ministers to consider the recommendations from the NDIS Review.

> **Box 11: Personal Care in Schools**
>
> Personal Care in Schools (PCIS) is provided to students to assist them with routine activities in both mainstream schools and specialist settings (including special schools and special units). This assistance generally covers meals, toileting and personal hygiene, dressing, mobility, along with complex supports (i.e. medicine, health supports). It is a highly integrated part of the student's school day and is linked to the educational supports used in the classroom.
>
> In 2021-22, the number of NDIS participants accessing state and territory delivered PCIS was around 43,000 across Australia. More broadly, there were close to 800,000 students across Australia who received an educational adjustment due to their disability (indicating that much like the NDIS, PCIS is targeted to a particular subset of the wider population of people with a disability).[542]
>
> As part of NDIS full-scheme agreements, governments agreed that while PCIS was a NDIS responsibility, it would be delivered on an in-kind basis until work was completed to better understand current services gaps and limitations and to develop credible service delivery models in the NDIS.
>
> Two separate government reports have not found systemic access or service quality issues.[543] The consultations that underpinned those two reports found that stakeholders generally were comfortable with the existing arrangements of funding and choice of carers being managed by the school/education system (with concerns raised around potential increased administrative burden placed on parents under an individualised NDIS model).

Moreover, even if the threshold for reforming PCIS were reached, the nature of delivery (intertwined with education support) and location of the service (in a classroom, which is a congregate setting) means an individualised delivery model is extremely challenging to design and implement and the benefits to students of such changes are unclear.

Box 12: Specialist School Transport

Specialist School Transport (SST) is provided by state and territory governments to students to safely transport students with disability to and from school, regardless of their participation in the NDIS.

In 2021-22, the total number of NDIS participants using SST as an in-kind support was around 29,800 students. Given that SST delivers services to more than just NDIS participants, it should be noted that there are a substantial number of students using SST that are not in the NDIS. In 2020 this amounted to around 8,000 students (around 28 per cent of SST users in the year).[544]

As part of NDIS full-scheme agreements, governments agreed that while SST was a NDIS responsibility, it would be delivered on an in-kind basis until work was completed to better understand current service gaps and limitations and to develop credible service delivery models in the NDIS.

Two separate engagements with SST stakeholders have found that parents and families are generally grateful for the service, and value it highly. However, consultations and analysis have found that there are significant access, service quality, and efficiency issues across jurisdictions.[545]

Key issues regarding SST include:

- Significant variability of service provision across jurisdictions (with the type of transport used, the number of students per vehicle, maximum length of time per trip, and the cost per student)
- The types of schools covered also varies across jurisdictions
- Inequitable service provision, transport to school is often only provided to students in special schools
- Inflexible program parameters that are not aligned with user needs
- Significant variance in efficiency
- Governments face a range of challenges in reforming SST to address these issues.

3.10.2. In-kind arrangements for the NDIS are inefficient and ineffective

We consider in-kind arrangements should not be long-term consistent with commitments in NDIS bilateral agreements. It is inefficient, discourages innovation and market development, and severely limits the choice and control of participants. However, to make a definitive decision on whether PCIS and SST remain in the scheme or are returned to sole state and territory responsibility, the case for reforming these two programs must be considered.

With respect to PCIS, our assessment of the available evidence is that there is a weak case for integrating PCIS formally into the NDIS, given that this program is effectively integrated into schools, families are very positive and change would require developing a new model of individualised delivery, which would be inefficient.

To understand the service gaps, limitations, and potential models for delivery, officials had led work with a primary focus on personal care provision in government schools. As a result, knowledge and data is less comprehensive on the provision of personal care supports in non-government schools. It is also unclear to what extent personal care is provided in non-government schools as a separately funded NDIS support.

Based on this assessment, PCIS should be removed from the scope of reasonable and necessary supports and be made the sole responsibility of educational service systems. However, this should be done under the condition DSS and the Australian Government Department of Education should undertake analysis on the provision of PCIS in non-government schools to assure decision makers there are no implementation challenges around access issues, which could include whether these supports are being funded in current NDIS packages. This will also address issues in data limitations for non-government schools.

It should also be noted that PCIS would fall within the scope of activities to be covered by the Disability Outcomes Council (see Action 23.1).

With respect to SST, our assessment of the available evidence is that there is a strong case for change. There are system-wide issues of access, where students receive a service based on where they live and/or the school they attend, rather than their level of need. In addition, the service quality varies significantly, with inefficiencies, unreasonable travel times and inflexible arrangements present across several jurisdictions. Lastly, current arrangements in many jurisdictions do not incentivise capacity building through travel training options as students age, instead promoting ongoing use of segregated specialist transport (which does not best prepare them for life after school).

Despite the strong case for change, there is presently no clear path to comprehensive reform if SST is retained in the NDIS. Equally, there is low likelihood of comprehensive service reform if SST is removed from the NDIS and returned to state and territory governments without consistent and nationally agreed benchmarks for access and quality, in addition to adequate funding and oversight mechanisms.

The specific challenges to progressing reform in the NDIS are the absence of a NDIS transport policy, the current lack of commissioning capability in the NDIA, and the fact that school transport is largely not suited to individualisation, unlike other services in the NDIS. The key challenges to reform of SST outside the NDIS are the absence of a service design that can bring all jurisdiction programs to a benchmark service standard and a lack of public commitment to reform, resulting in ongoing uncertainty for students with disability, their families, and providers. However, when weighing up these two sets of challenges and the steps needed to overcome them, we conclude that it will be most efficient and effective to deliver SST outside the NDIS.

As a result, we recommend reform of SST is best achieved if removed from the NDIS and returned as a responsibility of states and territories, based on a model where:

- SST service benchmarking is agreed, in the form of nationally consistent service standards that will ensure uniform access for students with disability (whether they attend a special school or mainstream school), maximum travel times (with students no longer regularly leaving early for school and returning home very late), and strong incentives for capacity building through travel training.
- DSS lead the detailed SST future state design engagement in collaboration with states and territories to develop the nationally consistent set of service standards. This should include a detailed jurisdiction-specific service redesign blueprint, to be implemented by each jurisdiction, where the core access and quality challenges in current programs in each state and territory are rectified, and subject to ongoing monitoring through binding bilateral agreements or under the ADS. In either scenario implementation and progress should be monitored by the Disability Outcomes Council (see Action 23.1).

We recommend DRMC should make a clear public commitment that reform of SST services will occur as soon as agreement is reached with all governments, and service redesign transition plans for each state and territory program will be released publicly to provide certainty to students, parents, schools and providers.

Action 2.16: Disability Reform Ministerial Council should agree to cease the use of 'in-kind' arrangements in the NDIS.

This is a long-running issue that needs to be resolved while balancing other priorities. Governments should consider removing specialist school transport and personal care in schools from the NDIS and returning them to be state and territory government responsibilities. Agreement to a national benchmark for service quality and access for specialist school transport should be a pre-condition.

Implementation detail:

The Department of Social Services (DSS) should work with the Australian Government Department of Education to undertake analysis on the provision of Personal Care in Schools in non-government schools to assure decision makers there are no implementation challenges around access issues. This should occur by end July 2024.

Australian governments should develop and agree to service benchmarking in the form of nationally consistent service standards for Specialist School Transport programs. This model:

- will need to ensure uniform access for students with disability (whether they attend a special school or mainstream school), maximum travel times (with students no longer regularly leaving early for school and returning home very late), and strong incentives for capacity building through travel training.

DSS should lead the detailed Specialist School Transport design engagement in collaboration with states and territories to implement the nationally consistent set of service standards. This should:

- include a detailed jurisdiction-specific service redesign blueprint, to be implemented by each jurisdiction, where the core access and quality challenges in current programs in each state and territory are rectified, and subject to ongoing monitoring through binding bilateral agreements or under Australia's Disability Strategy (see Action 2.9).

Chapter 2: Participant pathway

1. Key messages

- As a standard setter within the disability service system, the NDIS should ensure people with disability are at the centre of service delivery and empowered to exercise their rights. While the NDIS has delivered immense benefits to many people with disability, these benefits are not being shared equally.
- We recommend a complete rethink of the participant pathway – from finding out about and accessing the scheme through to finding, coordinating and making decisions about supports. This should ensure the NDIS experience is centred on the whole person and their disability-related support needs. We propose reforms to the overarching participant pathway, in addition to specific recommendations for children and families and people with psychosocial disability.

A fair, consistent and empowering NDIS experience

- Improvements are required across the participant pathway, including the approach to accessing the NDIS, setting budgets and implementing plans. The current approach to accessing the scheme is inequitable and is not always targeted to those people with disability who require the most support. The way participants then receive NDIS funding is adversarial and leads to inequitable funding outcomes. Participants also receive inconsistent and insufficient support to implement their plan.
- Changes are required to the way people apply for access to the scheme, how information is gathered from participants to assess need and how individual budgets are set. More support is also required for participants to create a plan for spending once their budgets have been set. This would make the planning process clearer, more consistent and less adversarial, and funding outcomes fairer and more consistent.

Support for all people with disability to better navigate mainstream and disability supports

- Finding and accessing foundational, mainstream and NDIS supports can be complicated, costly and time consuming for people with disability. While a number of different roles have been established to assist participants and their families to navigate the NDIS and surrounding supports, the variability and overlap of these roles has resulted in fragmentation of supports. Significant gaps also persist, which mean support is not consistently available to all participants.
- A new approach is necessary to deliver high-quality and consistently available support to assist people with disability and their families navigate NDIS, foundational, mainstream and community supports and services. This centres on the introduction of a local Navigator function to help people with disability find supports in their community and make the best use of their funding.

Support to empower people with disability to make decisions about their lives

- Participating in decision-making is a fundamental human right. Without appropriate support, some people with disability cannot independently exercise this right. The NDIS has increased the complexity of decision-making, but has not provided the support necessary for participants to navigate this complexity. We have heard participants do not have access to high quality

information to make informed decisions. People with cognitive disabilities in particular have limited opportunities to participate in decisions about their lives. Support for decision-supporters has also not kept pace with the increased demands of the NDIS. In parallel, there are insufficient checks on nominees' suitability and the supports they receive to execute their duties.

- More must be done to support participants to exercise genuine choice and control and to be able to make decisions about their lives. The NDIA should embed a best practice, rights-based approach to supported decision-making. Participants, families, nominees and other decision-supporters should be provided with access to high quality information and training to support them in their roles as decision-supporters. Nominees should also be provided with better information, support and training about their role, with appropriate oversight in place.

Better support for children and their families inside and outside the NDIS

- In Australia, one-in-five children have disability or developmental concerns.[546] The lack of support for parents, limited foundational supports, gaps in mainstream services and the delivery of NDIS funded early intervention supports mainly in clinical settings means that children and families are not getting the supports they need at the optimal time.
- Far more support should be available where children are and reduce the pressure on families having to access the NDIS for support. Implementing a holistic and connected continuum of supports for children with disability and developmental concerns should be an urgent priority for all governments.

Recovery-focused psychosocial supports in the NDIS and the broader mental health system

- The NDIS has delivered a significant increase in funding for disability supports for people with severe mental ill-health. While the NDIS has improved the lives of many, participants with psychosocial disability continue to experience lower community participation, employment and carer employment than other participants in the scheme. We have found the NDIS has not structured its processes or stewarded the provider market to support independence and personal recovery and failed to provide intensive, coordinated assistance for participants with highly complex needs. The NDIS also does not operate effectively within the broader mental health system.
- We must do better for people with psychosocial disability. A new psychosocial pathway should make access to the NDIS more straightforward for participants with psychosocial disability, and better connect participants to the wider support ecosystem. Taken as a holistic package, our reforms should reduce the gap between those in the scheme and those outside, enable better coordination with the broader health system, and improve outcomes for participants in the NDIS.

2. A fair, consistent and empowering NDIS experience

- We have heard overwhelming evidence from people with disability and families that the participant pathway needs a wholesale overhaul. Improvements are needed across the three

key areas of the participant pathway; accessing the NDIS, budget setting and implementing a plan.

- The current approach to accessing the scheme is inequitable and is not always targeted to those people with disability who require the most support. The way participants then receive NDIS funding is adversarial and leads to inequitable funding outcomes. Participants also receive inconsistent and insufficient support to implement their plan. For those who would benefit from and require early intervention, there is also no specific approach.

- Changes are required to the way people apply for access to the scheme, how information is gathered from participants to assess need and how individual budgets are set. More support is also required for participants to create a plan for spending once their budgets have been set. The proposed reforms would make the planning process clearer, more consistent and less adversarial, and funding outcomes fairer and more consistent.

Recommendation 3: Provide a fairer and more consistent participant pathway

🗐 Legislative change required

- 🗐 Action 3.1: The <u>National Disability Insurance Agency</u> should introduce a more consistent and robust approach to determining eligibility for access to the NDIS based on transparent methods for assessing functional capacity.

- Action 3.2: The <u>National Disability Insurance Agency</u> should introduce a new Access Request and Supporting Evidence Form and accompanying guidance to make the process of applying for NDIS access more transparent and simple.

- 🗐 Action 3.3: The <u>National Disability Insurance Agency</u> should change the basis for setting a budget to a whole-of-person level, rather than for individual support items.

- 🗐 Action 3.4: The <u>National Disability Insurance Agency</u> should introduce new needs assessment processes to more consistently determine the level of need for each participant and set budgets on this basis.

- 🗐 Action 3.5: The <u>National Disability Insurance Agency</u> should allow greater flexibility in how participants can spend their budget, with minimal exceptions.

- 🗐 Action 3.6: The <u>National Disability Insurance Agency</u> should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support.

- 🗐 Action 3.7: The <u>National Disability Insurance Agency</u> should reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes.

- Action 3.8: The <u>National Disability Insurance Agency</u> should implement reforms to the participant pathway using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

- 🗐 Action 3.9: The <u>Australian Government</u> should update and clarify legislation to support a more effective approach to determining access.

2.1. An effective approach to access is essential for the sustainable operation of the NDIS

Having an effective access pathway is an essential component of a needs-based scheme. An effective pathway makes sure that people with the greatest need do not face barriers that restrict or deny access to supports, while guaranteeing sufficiently rigorous decision-making.

There are serious challenges with the current access pathway. The process can be confusing and difficult to navigate. Gathering evidence for a request can be complex, time consuming and costly, and treating professionals don't always understand what evidence is required or how to present it. The complexity and expense of the process results in a poor experience for participants and deters some people from applying. It also means the NDIS is not as needs-based as it should be, and funding is not consistently targeted to those who need the most support.

The future access pathway should be clearer on who the NDIS is for and what evidence is needed to support an access request. This should be achieved through a dynamic and responsive Access Request Form to collect more consistent evidence to inform access decisions, a fair, transparent and consistent approach to assessing whether an applicant meets eligibility requirements, and a greater focus on needs by removing formulaic access under diagnostic Access Lists.

These reforms would improve the experience of making an access request and make it equitable for all applicants. The improvements will lead to fairer and more consistent access decisions. This must be supported by the proposed investments in foundational supports (see Chapter 1) so that people with disability who do not require an individualised budget are connected to supports outside the NDIS that meet their needs.

These proposed reforms are closely linked to a revised access pathway for children under the age of 9. The details of those reforms are set out in Section 5.3. This section is focused on access for people who are aged 9 or over. The intent and principles of both pathways are consistent.

2.1.1.   The current access pathway is inequitable and is financially and administratively burdensome for applicants

The current processes can mean that access to the NDIS is not always available for those with the greatest need. This is inequitable.

Some people with disability do not get access because of the complexity of the current process or barriers to gathering required evidence. In other instances, people may be granted access based solely on their disability type. This is because diagnostic lists are currently used to approve some requests. As a result, there can be insufficient consideration of an applicant's actual level of support need or functional impairment.

A fairer, more effective approach to access is essential to improve the experience of applicants and for the sustainable operation of the NDIS.

The different access pathways

Two distinct pathways to access the NDIS are set out in the *National Disability Insurance Scheme Act 2013* (NDIS Act):

- Section 24 (disability requirements).
- Section 25 (early intervention requirements).

However, the introduction of diagnostic lists (often called Access Lists) by the NDIA during the roll-out of the NDIS, intended to help with accelerated transition to the 'full scheme', resulted in an additional pathway that was not intended by the legislation. Some applicants experience very different evidence requirements to prove their eligibility (relative to applicants not covered by a diagnostic Access List). Figure 26 provides an overview of the different access pathways. The key distinction with the different Access Lists is that Lists A and D effectively provide automatic access based on diagnosis and List B provides streamlined access based on diagnosis.

Figure 26: Overview of the different access pathways

Section 24 of the NDIS Act	**Section 25** of the NDIS Act	**Access Lists**
Disability requirements Access under section 24 of the NDIS Act for people with disability with permanent impairment, substantially reduced functional capacity and lifetime support needs.	**Early intervention requirements** Access under section 25 of the NDIS Act for people with disability with permanent impairment who are likely to benefit from early intervention supports and are best supported by the NDIS.	**Automatic access:** **List A** Conditions likely to meet section 24 eligibility. **List D** Conditions for those under 7 likely to meet section 25 eligibility. **Streamlined access:** **List B** Conditions likely to meet permanent impairment criteria for section 24 or 25.

Making an access request for the NDIS

Currently, anyone who thinks they might be eligible for the NDIS must either contact the NDIS call centre to make a Verbal Access Request, or complete an Access Request Form and provide a Supporting Evidence Form if more information is required (in PDF format). The access request gathers required information from the applicant and their treating professional (where possible) to determine whether the applicant meets the eligibility requirements. The required information covers demographic and disability details, including early intervention requirements, functional capacity and support needs.

A person is eligible to access the NDIS only if they can prove they are:

- Younger than 65 when they apply
- An Australian citizen or permanent resident
- Living in Australia

- Meet the eligibility criteria of section 24 (disability requirements), or section 25 (early intervention requirements) of the NDIS Act.

We have been told that the challenges with the access pathway are apparent from the outset, and begin with developing an access request.

The current Access Request Form is complex to complete, particularly for people with cognitive impairment, low literacy, people from culturally or linguistically diverse backgrounds, and others who do not have existing experience with the NDIS. Although the Access Request Form was updated in 2021 to improve its usability, it remains a long and complex document. It has 28 pages and many questions are structured in ways that can be difficult for applicants and treating professionals alike to interpret.

> *"…But, as I'm aware, it's like still a lot of like forms you have to fill out. Like, I'm pretty sure I had to print out an Access Request form for my dad, who I'm pretty I'm 80% sure he is undiagnosed and he's had to like fill in 29 pages or something like that, it was just like the most, like it was a big pile and trying to staple it together was impossible. And I'm pretty sure like vaguely remembering when we got our first plan it was like piles of paperwork as well…" – Participant [547]*

The form requires applicants and their representatives to understand technical legal and medical information, including the granting of consent and what evidence to seek from appropriate professionals. The complexity of the form creates particular barriers for applicants who do not have informal support to assist them.

> *"Some sections [on the access form] were really complicated and not easy to read. A lot of information to read. Hard to understand what they are asking you to do." – Survey Respondent [548]*

> *"Current forms are cumbersome and inefficiently designed, with an emphasis on the requirement for the use of correct phrasing to obtain approvals as opposed to a narrative that conveys what supports the patient requires" – Royal Australian College of General Practitioners [549]*

> *"Access to the NDIS Access to the scheme is an arduous task for those with chronic illness and/or disabilities. During my two-year journey (approx.) attempting to navigate the application and appeals process, I encountered a lot of bureaucratic obstacles that deliberately sought to prevent granting me access to the scheme." – Person with disability [550]*

An access request can only be made via telephone or via the Access Request Form. The access forms are not readily available in Easy Read or other accessible formats. They are also static and usually provided in hard-copy. The forms cannot respond dynamically to information submitted by the applicant or their supporter or guide applicants to more relevant questions based on previous answers.

Critically, there is no integration of the access request with other data sources. This includes information from other government agencies to verify a person's identity in real-time or to populate information from other data sources such as *MyHealthRecord* or a treating professional's clinical information system. This means applicants and their treating professionals must provide all information manually, often repeating information already provided to other government agencies. There is a greater risk of errors or that inaccurate information could be provided. Lower quality or unverified information ultimately makes decision-making much harder for the NDIA.

Gathering evidence to support an access request

The failure of an access request can often be based on insufficient evidence. Proving eligibility can be a burdensome, intensive exercise. Applicants and health professionals alike often struggle to know what evidence is sufficient to enable a decision to be made.

Guidance on what evidence is required is not well integrated with the Access Request Form or the Supporting Evidence Form. As a result, some health professionals have turned to guides developed by other organisations to help them understand which terminology and phrases to use. They learn how best to present evidence based on the past experience of others rather than the specific circumstances of an applicant. The emphasis on correct phrasing to support decision-making comes at the expense of an accurate depiction of an applicant's needs. This incentivises professionals to attach their own reports to provide a narrative on the applicants' needs and circumstances. These issues ultimately mean insufficient or inconsistent evidence is often provided which makes it difficult for delegates to make consistent and equitable decisions.

> *"NDIA staff could clearly communicate the exact information they need for an NDIS Access Request to be granted. Rather than listing all the reasons why one failed" – Carer* [551]

> *"...many medical professionals struggle to know what level of information is required and are overwhelmed by NDIS processes." – MS Australia* [552]

> *"My child's specialists have to rewrite medical documents in 'NDIS speak' for the NDIA to accept them. These specialists are not trained in completing NDIS Access Request Forms... and nor should they have to be... I want help from specialists who are excellent in their field, not because they are adept in NDIS semantics." – Carer* [553]

The lack of guidance and responsiveness of the access forms means that applicants and treating professionals sometimes respond to questions for both the disability and early intervention requirements, or fully complete access requests for both pathways. This means time is spent answering questions that are not relevant or useful for the person making the access decision.

> *"[For] a client with psychosocial disability and Autism - a professional was required to fill in two Access Request Forms, one for each stream. However, evidence was provided on both conditions on the initial Access Request Form as well as adaptive function assessment results." – Australian Association of Psychologists Inc.* [554]

We have also heard that many applicants approach clinical specialists to provide evidence in support of access requests that could have been provided by a General Practitioner (GP) or allied health professional.

This is due, in part, guidance on how the NDIA evaluates different evidence sources, with greater weight placed on evidence from specialists. Applicants appear to have misinterpreted the guidance to mean an access request is more likely to be successful if evidence is provided by specialist rather than a GP or by an allied health professional. This leads to unnecessary additional expenditure and additional wait times by applicants fearful of being unable to prove their eligibility without a substantial volume of evidence from the most expensive health professionals.

> *"You shouldn't have to pay $1500 in specialist reports to get into the NDIS" – Survey Respondent* [555]

> *"Multiple documents and reports are required to PROVE that you deserve support" – Participant* [556]

> *"Assessment for autism, intellectual disabilities, and learning difficulties, often cost $1000-2000, which is a very high cost for many families... While there are some free options available to families, these are limited, and the waitlists for these services are often significantly longer than the ones quoted above." – Provider* [557]

Additional barriers to making an access request

The complexity of making an access request creates obstacles for applicants who are not able to navigate the system or obtain the reports and information required.[558] Barriers to access are greatest for people from culturally and linguistically diverse backgrounds, First Nations people, people from lower socioeconomic backgrounds, with low levels of literacy, applicants who don't have family or informal supports, and people with cognitive or psychosocial disability.[559]

The costs and time involved in collecting information are barriers for some people seeking access to the NDIS. The reliance on evidence, usually paid for 'out-of-pocket' means many people who would benefit most from the NDIS cannot prove eligibility in a timely way. Many people with disability who haven't applied or had an application rejected have indicated this is because "getting supporting documentation for the access request was too challenging".[560]

> *"I have been unable to access the NDIS because the application process is so horrible to engage with... I am suffering and there is nowhere I can turn for help. The NDIS needs to serve all disabled people, not just those who can work the system." – Person with disability* [561]

> *"Better communication from the NDIS access team [is needed] when impairment evidence is not sufficient and more evidence is requested, also intergenerational trauma and household challenges that are expected [to be provided] as evidence." – Anonymous* [562]

"I am so disabled that I cannot even manage to get help accessing the NDIS. My family is so overwhelmed just surviving day to day that there is no-one to help me. Doctors routinely ignore what I say and just tell me to eat better. They don't know what I eat. I cannot even get doctors to take all my health problems seriously enough to even get scans or test or advice or a diagnosis. My regular doctor retired. She never thought to suggest I am neurodiverse even though it's clear I am extremely so." – *Anonymous* [563]

The added dimension of the Access Lists

The introduction of Access Lists by the NDIA has created an additional pathway where different evidence requirements apply to some applicants. An applicant must have evidence of a particular condition to satisfy these different evidence requirements. The NDIA operationalised Access Lists to support the roll-out of the NDIS and manage the high number of access requests during the transition years. The diagnostic Access Lists were not removed when transition to the 'full scheme' was complete. Access Lists remain in place today.

Applicants with a condition on either List A or List D (for those under 7 years) effectively receive automatic access once they provide evidence of a condition included on the list. This is because it is assumed the nature of their diagnosis means they have a permanent impairment and are likely to meet disability requirements (for List A) or are likely to benefit from early intervention (for List D).

People with a condition on List B receive streamlined access because the evidence of a condition included on the list is also accepted as evidence of permanence. List B doesn't provide automatic access. It reduces the level of evidence to be collected by an applicant.

> **Box 13: The benefits and challenges of Access Lists**
>
> The Access Lists played an important role during the initial roll out of the NDIS. They helped reduce the burden on applicants with conditions that were clearly permanent and led to substantially reduced functional capacity. They also reduced the administrative burden on the NDIA to make timely access decisions and limit the creation of waitlists. They also provided a useful signal to potential applicants of what conditions would be likely to receive access to the NDIS.
>
> At the same time, the Access Lists have led to unintended consequences. Applicants with a condition on an Access List experience a significantly more positive access experience compared to others, particularly those who receive automatic access.
>
> This is in part due to a lack of improvements to the access pathway to lift the experience of all applicants, but the lists have however created issues with fairness. Two applicants with the same level of functional impairment and need may have very different experiences of the access pathway and may have different outcomes based solely on whether a diagnosis is or is not included on a list. There is a lack of clarity around how particular conditions came to be included on the lists while others were not.

The Access Lists also contribute to inequity between applicants from different socioeconomic backgrounds. The reliance on diagnosis means that applicants that are able to pay for specialist appointments for diagnostic tests and/or to shorten waiting time will be able to access the NDIS faster than those who cannot. This creates an equity issue if access to NDIS supports is influenced by a person's background rather than need.

The reliance on diagnosis to be eligible for the Access Lists has also arguably moved the waiting list from the front door of the NDIS to the front door of specialists with many people with disability now facing months or years to access an appointment.

The missing early intervention element

The NDIS is based on social insurance principles that use actuarial estimates of long-term and lifetime costs. It is based on the concept that support, investment and early intervention may help the long-term functional capacity of people with disability.[564]

The early intervention access pathway (section 25 of the NDIS Act) is one of the key ways the insurance principles of the scheme are realised in practice. That a second distinct way to access the NDIS was created reflects the clear foundational intent to take a different approach to supporting some people with disability who do not meet the disability requirements (in section 24 of the NDIS Act).

The original vision for the NDIS was to fund cost-effective interventions aimed at reducing the day-to-day impacts of long-term disability over time. The Productivity Commission linked eligibility for early intervention to consideration of whether the intervention would be safe, significantly improve outcomes and be cost effective.[565] This was for both children and adults – the addition of developmental delay as a criteria for children came after the original Productivity Commission report in 2011. It is noteworthy that the definition for developmental delay in the NDIS is almost an exact copy of the definition for definition for developmental delay used in the Victoria's *Disability Act 2006* (replacing the *Intellectually Disabled Persons' Services Act 1986*). It has not been refined or updated for use within the NDIS despite it being the largest access point for early intervention supports.

Box 14: The evolution of early intervention in the NDIS

Productivity Commission (2011):

"The Commission proposes the early intervention group encompasses people for whom there is good evidence that the intervention would be safe, significantly improve outcomes and be cost-effective. Early interventions would seek to reduce the impact of disability for the individual and the wider community. They would typically be of a given duration and occur as soon as the disability is first identified or appears, where there is a discrete change or deterioration in the disability, or at particular transition points in an individual's life."[566]

Despite this clear vision, access to the scheme through the early intervention access pathway (section 25 of the NDIS Act) has been operationalised without a strong link between eligibility and clear evidence that early intervention would be safe, significantly improve outcomes and be cost effective. A scheme-wide approach to early intervention remains unclear.

> *"The early intervention pathway for adults is unclear and not well understood by planners and assessors. Many people do not know that they can access it, how it can support them, what supports are available and what evidence is needed to meet the criteria." – MS Australia* [568]

The key distinguishing test of the early intervention criteria is that the CEO is satisfied that the provision of early intervention supports for the person is likely to benefit the person (based on section 25(1)(b) and (c) of the NDIS Act). Figure 27 summarises the key eligibility criteria across the different access pathways.

Determining if a person is likely to benefit from a particular early intervention support should require a strong theory of change based on the needs of the individual, the expected service response, and evidence about the benefits and cost-effectiveness of that service response. However, there is not currently a rigorous process to establish this theory of change to support the CEO's decision-making.

Figure 27: Summary of eligibility criteria across different access pathways

	Disability requirements	Early intervention requirements	
		Developmental delay	Permanent impairment
Evidence of impairment	Applies	Applies	Applies
Evidence impairment is, or is likely to be, permanent	Applies	-	Applies
Lifetime support	Applies	-	-
Substantially reduced functional capacity	Applies	Applies	-
Reduction in capacity for social or economic participation	Applies	-	-
Extended duration of interdisciplinary care required	-	Applies	-
Likely to benefit by reducing future support needs	-	Applies	Applies
Likely to benefit functional capacity; or strengthen informal supports	-	Applies	Applies
Not more appropriately supported by another service system	-	Applies	Applies

The inequity of access to the NDIS

The majority of people who complete an access request for the NDIS are found to be eligible (85 per cent of all access requests have been successful as of June 2023).[569] However, there are significant variances in the rate of successful access requests by gender and disability type. This is particularly evident between those primary disability groups included on an Access List and those that are not.

There are clear differences in access rates based on gender. Since the beginning of the scheme, males have an access rate of 89 per cent in comparison to 80 per cent for females and 79 per cent for 'other' (Figure 28). This in part reflects inequity in the diagnosis of disability types within high access success rates such as autism, global development delay, and intellectual disability.

However, there are also stark differences in access rates by gender within some primary disability groups (Figure 28). Females had lower access rates than males for all primary disability groups except for autism, global and developmental delay and multiple sclerosis. The applicant group 'other' has lower access rates than males for all but the "missing" primary disability group. Developmental delay was the only primary disability group where the applicant group 'Other' doesn't have a significantly lower access rate than males.

Figure 28: Summary of the difference in access met rates by gender and primary disability group as of June 2023[570]

Primary disability group	Male - Percentage of access decisions eligible	Female - Percentage of access decisions eligible	Other - Percentage of access decisions eligible
Acquired brain injury	93%	91%	85%
Autism	97%	97%	95%
Cerebral palsy	97%	96%	91%
Developmental delay	98%	98%	97%
Global developmental delay	99%	99%	96%
Hearing impairment	90%	87%	85%
Intellectual disability	96%	95%	89%
Multiple sclerosis	90%	90%	77%
Psychosocial disability	75%	66%	57%
Spinal cord injury	95%	92%	89%
Stroke	86%	84%	78%
Visual impairment	88%	86%	76%
Other neurological	81%	79%	72%
Other physical	50%	38%	31%
Other sensory/speech	49%	44%	25%
Other	45%	31%	32%
Missing	94%	94%	98%
Total	**89%**	**80%**	**79%**

There are also stark differences in the success of access requests across primary disability groups (Figure 29). Understandably, conditions included on List A or D have much higher rates of successful access decisions, including global developmental delay, cerebral palsy, autism, intellectual disability and spinal cord injury. Whereas people with psychosocial disability in particular have a significantly lower proportion of successful access requests compared to people in other primary disability groups.

Figure 29: Summary of the difference in access met rates by primary disability group[571]
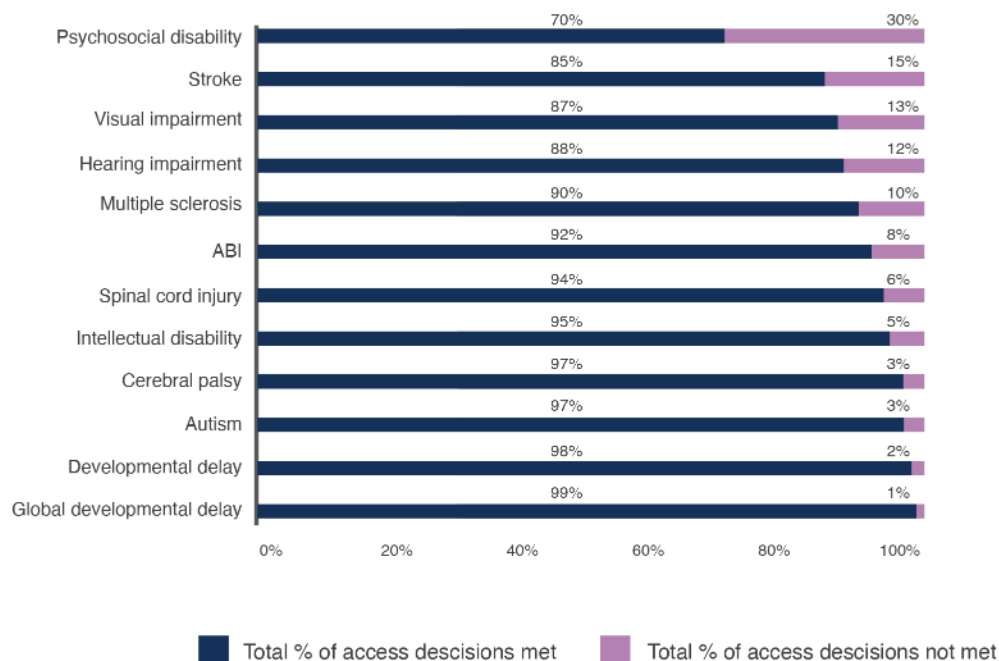
The difficulty some applicants face is highlighted in the number of participants who had at least one unsuccessful access request. These are participants who have made unsuccessful access requests and then have ultimately been found to be eligible on a later access request. This discrepancy may be due to insufficient evidence being provided by an applicant or treating professional in earlier access request, or because of progression of a condition over time.

> *"It took several times to get NDIS access. The first time I applied they told me I needed more evidence… things went a lot better when I took an advocate with me who knew the right words to use" – Physical Disability Australia [572]*

As of March 2023, 6 per cent of active participants (approximately 36,500) have had to make multiple access requests before being successful.[573] Similar to the trends described above, some primary disability groups have much higher rates of re-application before being successful. Psychosocial disability, other physical, multiple sclerosis and other neurological experienced the highest rates of re-application (Figure 30).

Figure 30: Number and proportion of active participants who made multiple access requests as of 31 March 2023 (*Intellectual disability includes Down syndrome)[574]
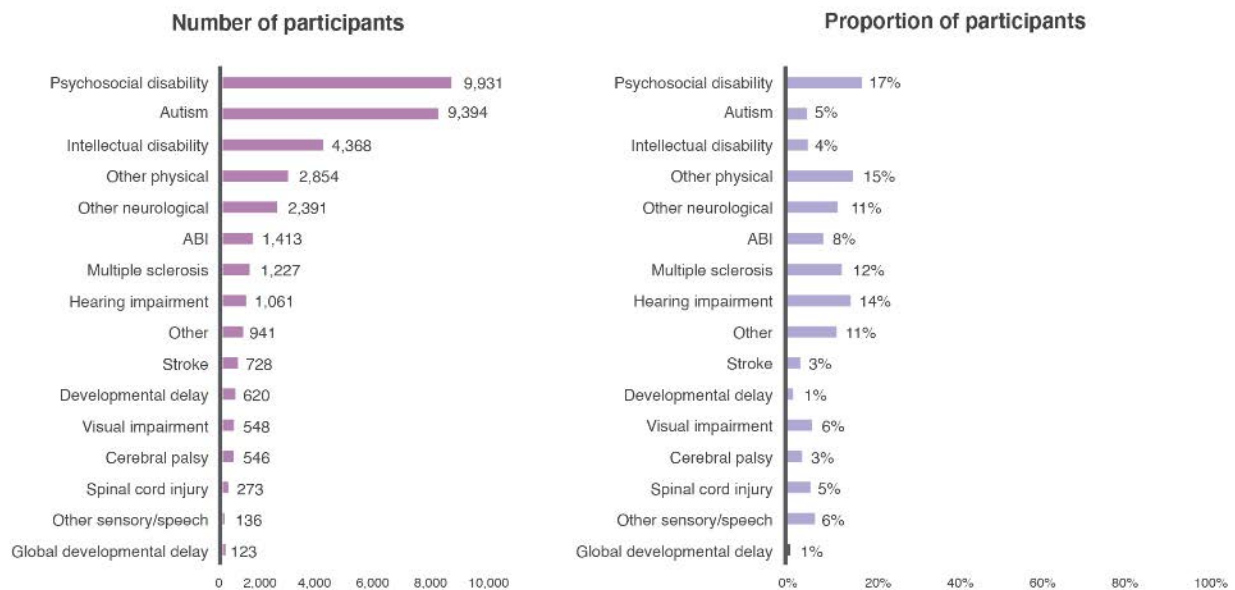
2.1.2. Accessing the NDIS should be fairer and more consistent

We propose a coherent package of essential reforms to the NDIS participant pathway. Changes to the access process are key to these reforms.

The future pathway should be clearer on who the NDIS is for and what evidence is needed to support an access request. The experience of making an access request should be improved and outcomes should be fairer and more consistent.

The proposed changes (summarised in Figure 31) aim to address the inequities of the current access pathway by ensuring that eligibility is not determined by how much evidence an applicant can obtain, whether their treating professional used key terms or phrases, or because a specific diagnostic condition was included on an Access List.

These changes will clarify who the NDIS is for, move the focus from diagnosis to need and ensure participants receive the support they require. These proposed changes must be complemented by our recommendations to significantly increase the accessibility, inclusion and availability of support outside of the NDIS (see Recommendations 1 and 2).

Figure 31: Overview of the four main areas of change proposed for access to the NDIS

1. Making the process of applying for NDIS access more transparent and simple	• This will require a new dynamic online Access Request and Supporting Evidence Form and accompanying guidance. • It should make clear what information is required and why. It should be responsive to information as it is entered and provide real-time guidance. • Improvements to existing verbal or printed access request options should also be made.
2. Clarifying definitions of key eligibility criteria in the NDIS Act	• This requires the introduction of a definition of 'substantially reduced functional capacity' for section 24 of the NDIS Act, 'substantial developmental delay', and 'likely to benefit' for section 25 of the NDIS Act. • This requires clarification of the level of need that can and cannot be met through foundational supports. • Both should clarify who the NDIS is for and make clear access requirements.
3. Standardised approaches to determine whether eligibility criteria is met	• This requires processes to be linked to proposed definitions in the NDIS Act. • This requires functional assessments to link to functional capacity for section 24 of the NDIS Act, developmental and behavioural evaluation assessments to link to developmental delay for sections 9 and 25 of the NDIS Act, and needs assessments to link to section 25 of the NDIS Act. • This should increase consistency in decisions and ensure the NDIS supports those with greatest need.
4. Removing automatic access under the Access Lists	• This will require the NDIA to remove automatic access through the diagnostic Access Lists. Lists should be replaced with an approach of streamlining evidence requirements wherever possible to ensure only essential information is collected for all applicants seeking access. • This will increase the equity of access to the NDIS once the additional changes outlined above have also been introduced. Those changes are required to facilitate the removal of automatic access by virtue of diagnosis. The current Access Lists should not be removed until the other changes proposed are in place.

Making the process of applying for NDIS access more transparent and simple

We propose a simpler and more guided process for making an access request. This would be delivered through significant changes to how an access request is made, including revisions to the existing Access Request Form and Supporting Evidence Form.

These changes are necessary to respond to the current challenges of understanding what is required and in what form, as well as subsequent issues, with sufficiency and consistency of evidence provided. Our proposals would have the dual benefit of improving the experience for applicants while also improving the standard and consistency of evidence the NDIA has at hand to inform decisions.

The proposed process would be more focused on seeking evidence from the applicant, as the expert in their own lives and what they need, in the easiest way possible while also collecting necessary evidence from treating professionals.

Under the proposal, applicants and treating professionals would be able to complete a dynamic and responsive Access Request Form and Supporting Evidence Form. For applicants using an online form, the questions would adjust as information is populated. For example, questions may adjust based on communication requirements, language, personal circumstances, and which evidence requirements are applicable. Consistent guidance for each question will also be integrated into the form to clarify the questions and ensure correct information is provided.

For applicants making Verbal Access Requests, the same principles will apply. Applicants will be asked for information progressively, with changes based on their submitted answers. Printed forms will remain available.

For all formats, applicants should be able to seek assistance from a Navigator to make their Access Request. The Navigator should especially be offered for any applicant who may require support to use digital systems. The details of what Navigators are and the role they will play are set out in Section 3.1.6.

Once the applicant has completed their responses, they would be able to add a link to their treating professional to complete relevant sections. There should be significantly more guidance embedded in the digital form to explain key terms and what is required at each stage for treating professionals. The applicant could choose whether to give consent to share their answers with the treating professionals, or have them add additional information as supporting evidence. The online form should also be available to professionals to provide evidence regardless of what format the applicant chooses to provide their answers. This could allow an applicant to make a Verbal Access Request that is then linked to written evidence provided by a treating professional using an online form.

To ensure transparency the full list of questions and guidance would be made publicly available without having to complete the form.

Clarifying definitions of key eligibility criteria in the NDIS Act

We propose far greater clarity for some of the key eligibility criteria used to determine access to the NDIS. This would be achieved by defining these key eligibility criteria in ways that allows them to be linked to the outputs of an assessment process which allows comparison of applicants with their peers.

These changes are needed to respond to the current inequity in access to the NDIS. They will enhance transparency about the purpose of the NDIS, who legislation intends it is for, and lead to better, fairer and more consistent access decisions.

There are three main areas where an agreed definition is required that can be linked to an assessment process:

- 'Substantially reduced functional capacity' in section 24(1)(c) (disability requirements) of the NDIS Act.
- Substantial developmental delay' is proposed to replace 'substantial reduction in functional capacity in section 9 of the NDIS Act as part of the definition for developmental delay. This definition is linked to section 9 (definitions) and 25(1)(a) (early intervention requirements) of the NDIS Act. More detail on the approach for those under the age of 6 accessing the NDIS with developmental delay is provided in Section 5.3.
- 'Likely to benefit' in section 25(1)(b) and (c) (early intervention requirements) of the NDIS Act. This should be supported by clarification of the level of need that can (and cannot) be met through foundational supports in relation to section 25(3) (early intervention requirements) of the NDIS Act.

<u>Substantially reduced functional capacity and substantial developmental delay</u>

The definitions should establish clear thresholds to determine whether an applicant has met the relevant eligibility criteria. This should include an agreed definition of substantially reduced functional capacity to give more clarity to applicants and consistency in decision-making.

This definition should be linked to the outputs of a functional assessment process that can measure the impact of impairment and allow applicants to be compared to their peers (norm-referenced assessments). The definition could then be operationalised through measuring standard deviations from the mean.

An example for substantially reduced functional capacity could be that the applicant has been assessed as being two standard deviations below the mean for one functional domain, given their age, or one and a half standard deviations below the mean for two or more functional domains, for their age. This definition is provided as an example only and further work will be required to identify appropriate thresholds, particularly across multiple domains. This could mean that an applicant is eligible based on results for a single domain, or they may be eligible based on the cumulative impact across multiple domains. It is critical that a broad range of domains is measured.

This approach could apply similarly to substantial developmental delay for children under the age of 6 where age-appropriate developmental domains are used.

We are not proposing a final definition. That essential task should be completed only after the framework has been developed and appropriate assessments chosen, tested and agreed. Design and testing must involve significant engagement and collaboration with people with disability, families, representative organisations, functional measurement experts and researchers and health professionals.

The thresholds should be set using a norm-referenced approach (rather than a criterion-referenced approach). Results for the individual must be compared to the results of their peers. This is a norming-process where individuals are plotted onto a bell-curve to determine those with the highest and lowest levels of need. As Figure 32 shows, using standard deviations from the mean

provides an approach to identify those with the greatest need relative to their peers and so aligns with the original structure intended for the NDIS.

Figure 32: Simplified illustration of how assessment results may be normed to create a bell-curve that links to the results of their peers
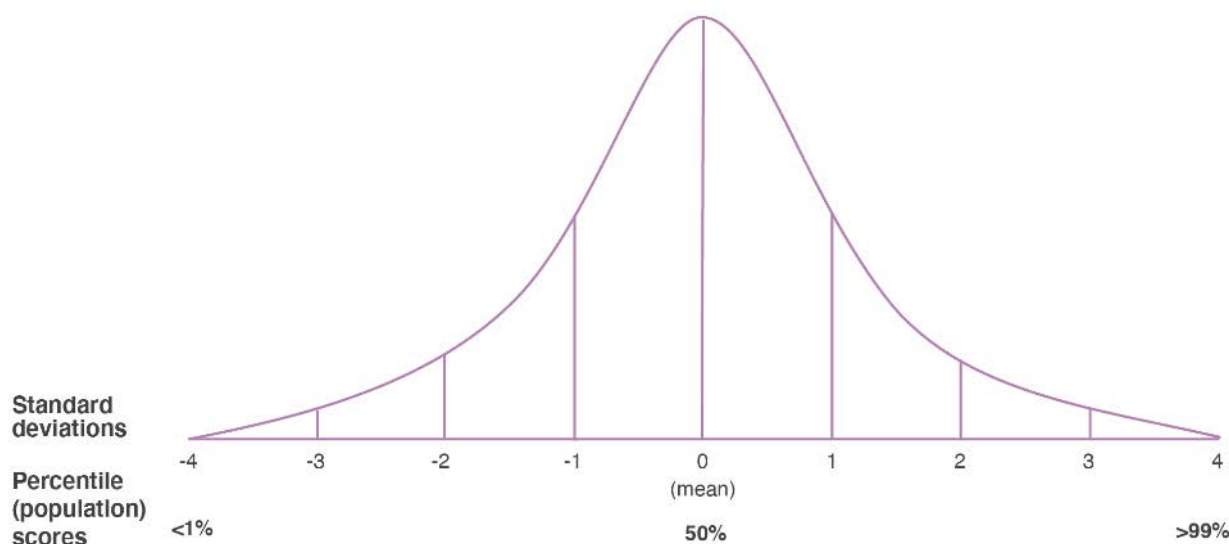
Likely to benefit and whether a person is appropriately supported by the NDIS

A similar but distinct approach would be needed to link the other key early intervention requirements to a consistent and fair assessment process.

Requiring all applicants to have substantially reduced function to access the NDIS through early intervention would defeat the purpose of early intervention as some people would miss out on support during the most critical period before function is substantially and permanently impacted (particularly for people with progressive conditions). Applicants accessing early intervention support through developmental delay would, however, still be required to have substantial delay.

This additional approach links the proposed needs assessment (see Actions 3.4 and 6.4) to the existing criterion of "likely to benefit" and whether the early intervention support for the person "could be appropriately met" by mainstream or new foundational supports. The latter is particularly relevant for the groups for whom significant investment has been recommended through targeted foundational supports. This change should not be introduced without the investments in foundational supports being made by government.

The proposed needs assessment should provide a more consistent basis for CEO determination of "likely to benefit" and whether early intervention supports can be met through foundational supports (see Recommendation 1). This is because these criteria relate to the level of need and potential service response, both of which are core elements of conducting a needs assessment. This would mean that applicants accessing the NDIS through the early intervention pathway would not be deemed eligible until after they have completed a needs assessment. For clarity, those accessing

through section 24 would complete a functional assessment to inform access and those coming through section 25 would complete a needs assessment to inform access.

To be eligible under section 25, there should be a clear theory of change that a period of early intervention funded by the NDIS would significantly improve outcomes and be cost effective. This theory of change should be tested through a needs assessment process (see Section 2.2.2 for more detail on the needs assessment). The approach for making these considerations should be included in the NDIS Rules.

Similar to the approach for functional capacity and development delay, the results of a needs assessment should be normed to compare the applicant against their peers. This requires that the needs assessment can generate a needs score, index or intensity level (for example, the existing Support Intensity Scale (a needs assessment) generates a score based on a rating of how frequent a support is needed, how long it takes to provide and the type of support needed for life activities in the areas of home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy). This would ensure that the NDIS supports those with the highest level of need. This is consistent with the original intent that "Tier 3 [NDIS] would be targeted at the much smaller group of people with significant care and support needs".[575]

The permanence criteria

The 2022 Federal Court decision in *National Disability Insurance Agency v Davis* is likely to have significant implications for how the permanence eligibility criteria works in the future.[576] Currently, an applicant is required to have an impairment(s) that is, or is likely to be permanent. The only exception to this requirement is for young children under the age of 6 accessing the NDIA with developmental delay.

The purpose of the permanence eligibility criteria is to distinguish those who have an impairment that can be effectively addressed through treatments (such as through the health system) from those whose impairment is permanent and appropriately addressed through disability supports in the NDIS. This is a key challenge for the boundary between the NDIS and health systems.

When considering if a person meets the permanence eligibility criteria, the *NDIS (Becoming a Participant) Rules* (rule 5.4) require that 'an impairment is, or is likely to be, permanent only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.'[577] The key words of available and remedy had been interpreted by the NDIA to mean that there was a treatment that an individual could theoretically access and that a remedy would likely relieve the individual's impairment.

The Federal Court took a different view to both of these interpretations. It found that applicants are only obliged to engage in treatments that are 'practically available' to them. This means treatments that can be actually accessed, rather than theoretically. Introducing the practicalities of being able access treatment due to cost, location or conditions.[578]

The Federal Court also found that remedy should be understood to mean 'something approaching a removal or cure of the impairment'. This practically means impairments that might be

substantially alleviated or managed through treatments should still be considered permanent (as they wouldn't reach a level of curing the impairment).[579]

These interpretations have arguably widened eligibility to the NDIS by restricting treatments to those that are practically available and requiring remedies to achieve a higher bar. A key challenge is that it may result in applicants with chronic health conditions accessing the NDIS on the basis that medical treatments are not practically available due to cost or waitlists, and that any treatment is unlikely to cure a chronic condition. This is not consistent with the intent of the NDIS and means that the NDIS would be funding supports that are not linked to disability and should be provided by the health systems.

There should be further work undertaken to strengthen the permanence criteria and to develop a simultaneous response that ensures there is greater availability and affordability of treatments. This is necessary to ensure the NDIS remains sustainable and able to meet the needs of people with disability into the future and ensure that people are not stuck between the health system and the NDIS without support.

Approaches to determine whether eligibility criteria are met

We are proposing to use assessment processes to determine whether the key eligibility criteria described in the previous section have been met.

For example, this would be implemented by introducing a requirement for applicants to undergo a

- Functional capacity assessment for those over the age of nine and accessing the NDIS through section 24
- Developmental and behavioural evaluation assessment and a needs assessment for those under the age of six with developmental delay and accessing the NDIS through section 25
- Needs assessment for those accessing the NDIS through section 25.

These assessments would be paid for by government and linked to the clarified definitions of the key eligibility criteria described in the previous section.

This will lead to a more equitable approach to accessing the NDIS by removing financial barriers to applicants having the required evidence to support an access request and increasing consistency in decision-making. It will ensure that people with the same level of functional capacity (all other things being equal) have the same access outcomes regardless of their diagnosis or ability to source expert reports. This will also mean that people with disability shouldn't be asked to regularly re-prove their disability once they have met access under these more robust processes.

> *"Every 2 years I have to prove my son's disability again. It can cost up to $1000 every 2 years." - Parent[580]*

Figure 33: Link between the key eligibility criteria our proposed approach to use valid assessments to determine whether key eligibility criteria have been met

Specific access pathway	Key eligibility criteria	Relevant assessment
Section 24 (disability requirements) of the NDIS Act: Applicant over the age of nine with an impairment that is, or is likely to be, permanent and with lifetime support needs	A. Substantially reduced functional capacity	A. Functional capacity assessment
Section 25 (early intervention requirements) of the NDIS Act: Applicant under the age of 6 with developmental delay and is likely to benefit from early intervention (see Section 5.3.8)	A. Substantial developmental delay	A. Developmental and behavioural evaluation assessment
	B. Likely to benefit from early intervention	B. Needs Assessment
	C. Whether need for early intervention support can be met elsewhere	C. Needs Assessment
Section 25 (early intervention requirements) of the NDIS Act: Applicant of any age who has an impairment that is, or is likely to be, permanent and is likely to benefit from early intervention	A. Likely to benefit from early intervention	A. Needs Assessment
	B. Whether need for early intervention support can be met elsewhere	B. Needs Assessment

<u>Section 24 (disability requirements) of the NDIS Act: Applicant over the age of 9 with an impairment that is, or is likely to be, permanent and lifetime support needs</u>

An applicant over the age of nine seeking to access the NDIS would undertake a validated functional capacity assessment (applicants under the age of nine are required to access the NDIS through the early intervention access pathway).

The only exceptions to this would be when the treating professional is able to provide existing information that the applicant has substantially reduced functional capacity (e.g. an assessment was completed for an alternative purpose which is directly comparable and acceptable for the NDIS).

The functional capacity assessment could be undertaken by the applicant's treating professional provided they have been trained and approved to use the validated assessment instrument. An

applicant could choose an alternate assessor, or an assessor sourced by the NDIA if needed. In any scenario, the cost of the assessment should be met by government (ideally through Medicare).

In a limited set of circumstances, a decision about eligibility may be more difficult because of the complexity of the disability, interactions with health conditions, and / or the characteristics of the applicant's circumstances. In this scenario, the NDIA may request additional evidence. This additional evidence would be at the cost of government and could include an additional functional assessment by an independent professional. The information collected would then be reviewed by an NDIA-appointed panel to make a decision. The panel should include an NDIA chair and delegate, as well as individuals independent from the NDIA with clinical and disability expertise (including people with lived experience). The scenarios in which this variation would be permitted by the NDIA, and the process of having the information reviewed by the panel, would be included in the NDIS Rules for transparency.

There must be significant work undertaken to identify, test, refine and validate any functional capacity assessment(s). Transparency will be essential. This approach will require the NDIS Experience Design Office (see Action 24.3) to work with at a minimum (although not limited to) participants and applicants, representative organisations, experts in functional assessment, researchers, and health professionals.

All existing functional capacity assessments must be tested with individuals and groups within the disability types for which they have been designed to inform and validate (or rule out) their use as part of the new access process.

Where appropriate functional capacity assessment instruments do not currently exist, or are not fit for this specific purpose, new assessments should be designed and validated with the groups for whom they will be used. This development process should build on existing work that has already established a clear need for a new assessment of functioning for some groups and disability types.

Any assessment process should cover a broad range of domains to be seriously considered for use (e.g. cognitive, language, social-emotional, motor and adaptive behaviour). There should be an accepted basis for comparing results from two or more acceptable instruments that might be used to assess function in, and across, domains. Any assessment considered should take into account that disability can fluctuate over time, and that results may vary based on the different environments, social, cultural and economic circumstances in which a person lives.

The assessment instrument(s) we envision must:

- Be linked to the agreed definition of substantially reduced functional capacity (see Section 2.1.2)
- Be norm-referenced to measure functional capacity in a way that allows applicants to be compared to their peers
- Collect the minimum amount of evidence necessary on level of impairment and permanence of that impairment to be able to satisfy the NDIA delegate that relevant eligibility criteria have been met

- Map to the World Health Organisation International Classification of Functioning, Disability and Health to enable consistency of data collection and tracking of outcomes across service systems
- Be undertaken by an applicant's treating professional, if they are trained and approved in the use of the assessment, or an NDIA-funded, trained and approved assessor (when required)
- Be designed with and acceptable to the people and groups for whom it will be used to assess NDIS eligibility.

Outcomes of the assessment will be considered alongside self-reported information and other evidence to assist the NDIA delegate in making an access decision. An applicant would still also need to meet other relevant eligibility criteria in order to access the NDIS through section 24 (disability requirements).

Section 25 (early intervention requirements) of the NDIS Act: Applicant under the age of 6 with developmental delay and is likely to benefit from early intervention

Applicants under the age of 6 with developmental delay seeking to access the NDIS would be required to undertake a developmental and behavioural evaluation assessment. This approach is similar but distinct from the approach for functional capacity above. It is described in more detail in Section 5.3.8.

Section 25 (early intervention requirements) of the NDIS Act: Applicant of any age who has an impairment that is, or is likely to be, permanent and is likely to benefit from early intervention

An applicant of any age who requires early intervention supports and is seeking to access the NDIS would be required to undertake a needs assessment. We expect this to primarily relate to children, those with progressive neurological conditions and those with psychosocial disability.

Applicants would only become eligible for a needs assessment once they have already satisfied the remaining eligibility criteria for access. That is, the NDIS delegate would be satisfied that all other criteria have been met and believes it is appropriate for the applicant to undertake a needs assessment. At this point in the reformed participant pathway, all applicants would have been otherwise required to undertake a needs assessment to determine the budget anyway.

A needs assessment is proposed for this pathway to ensure that early intervention can also be provided prior to an applicant experiencing a substantial loss of functional capacity. It should be able to determine need for those with episodic conditions who may have highly varying levels of functional capacity at different times. There will need to be careful design to consider how assessments completed at a point in time can work for those with episodic conditions.

Importantly, the results of a needs assessment should also be normed to compare the applicant against their peers. This would ensure that the early intervention pathway remains focused on people with the highest needs. It must not become an 'easier' pathway to access the NDIS because the applicant does not need to prove substantially reduced functional capacity.

The needs assessment would be undertaken by a skilled and qualified NDIA Needs Assessor who has disability expertise and is a trained allied health practitioner or social worker/youth worker or similar (see Section 2.2.2 for more detail on the requirements for NDIA Needs Assessors).

This would require reliable and valid assessment processes that provide a structured approach for the Needs Assessor to identify support needs and intensity. To develop this new approach, existing support needs assessments should be tested with the groups and disability types for whom they were validated and inform the design of any new needs assessment. Particularly for children and families, those with progressive conditions and those with psychosocial disability

These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8). See Section 2.2.2 for more detail on needs assessments and approach to transparently developing a suitable approach with the disability community.

The needs assessment instrument(s) will need to:

- Be linked to the agreed definitions of:

    - Likely to benefit from early intervention (see Section 5.2).

    - Whether need for early intervention support can be met elsewhere (see Section 5.2).

- Generate a transparent and valid needs score, index or intensity level
- Be norm-referenced to measure need in a way that allows applicants to be compared to their peers
- Help to establish a theory of change for the expected benefit of a period of early intervention. That is, if certain supports are provided by the NDIS, then foreseeable benefits will be expected to significantly improve outcomes and be cost effective
- Collect the minimum evidence necessary to satisfy an NDIS delegate that:

    - The provision of early intervention supports for the applicant is likely to benefit the person

    - Their level of need cannot be reasonably met by mainstream or new foundational supports

- Generate a reasonable and necessary budget for the applicant if they are found to be eligible. See Section 2.2.2 for more detail on how needs assessments will be used for budget setting.

This approach will ensure those who would benefit from the NDIS most are able to access supports. It will also ensure those who would be better supported by services outside the NDIS are directed to the appropriate supports through a targeted referral (underpinned by the needs assessment process), which will reduce cost pressures on the scheme.

> *"...we propose the International Classification of Functioning (ICF) as a potential framework to build the assessment process. The potential benefits of the ICF framework to the NDIS, including in the development of person-centred assessment, have been previously articulated in detail.*
>
> *The introduction of a combined functional assessment (focused on understanding and measuring impairment) and support needs assessment (focused on identifying tailored*

supports to reduce participation restriction) framework based on the ICF could lead to more accurate, evidence-based and internationally-recognised understanding of disability, including psychosocial disability, alongside identification of support needs.

Re-conceptualising disability within the NDIS, in terms of ICF concepts to replace the widely criticised primary disability/diagnostic focus, has the potential to bring real change to the entire NDIS experience for people with disability, alongside enhanced capacity to measure outcomes and build data to continuously improve the NDIS." – Occupational Therapy Community of Practice [581]

"For children experiencing developmental delay or disability, their families and carers are faced with a complex network of services, application processes and funding streams before they can even access early intervention supports. Even with the best of intentions, the current system can be difficult to navigate and creates burdens and barriers for families, which in turn fails to facilitate smooth access to services." – Early Childhood Intervention Practice Network [582]

Access lists

In addition, we propose removing automatic access to the NDIS under diagnostic Access Lists.

Automatic access should be replaced by a principle of streamlining evidence requirements wherever possible to ensure only essential information is collected for all applicants seeking access. Applicants with a condition eligible for streamlined access would not be granted automatic access.

This streamlined approach could apply where applicants have existing evidence from a treating professional that provides a strong indication that they have a permanent impairment and/or have substantially reduced functional capacity.

A streamlined approach is recommended in recognition of the benefits of having transparent ways of ensuring that evidence is not requested where it is clearly duplicative, and that an access decision can be made using previously provided evidence. Streamlining evidence requirements would also reduce wasteful spending on evidence for applicants, the NDIA and the health system.

To introduce a streamlined access pathway, an objective methodology should be developed to determine which conditions are eligible for this pathway and what additional evidence is required for those conditions. This methodology should be developed in consultation with people with disability, representative organisations, health professionals and researchers and be published for transparency. The methodology will need to balance reducing unnecessary burden with ensuring robust and tailored access decisions. Valid functional assessments through treating professionals will still be required for most applicants to ensure that the NDIS is able to capture need beyond diagnosis, and support those with the highest need.

2.1.3. How our proposals would work

The case studies below provide further detail on how our proposals would work in practice. The case studies highlight differences between how the current access pathway works and the future access pathway would work for different applicants:

Case study 5: Sophia, 11 years old, female, Autism Level 2 diagnosis, section 25 (early intervention requirements) access request

Sophia had previously been identified as socially anxious and having sensory issues, especially with noise. In the last year she has been having more difficulty communicating at school and participating in the classroom. Her teachers have noticed that she has difficulty concentrating and relating to her peers.

Sophia is having regular 'meltdowns' when she arrives home from school and her younger brothers are playing games and running around inside the house. Her parents are hopeful that this is a phase that she will grow out of. Sophia is their first child and her parents aren't sure what to expect as she gets older.

Current access pathway

- Sophia's school raises concerns with her family. A new teacher has noticed she is often forgetting to bring her school bag, mixes up instructions and struggles to recall some of classmate's names. The teacher believes she needs more help in the classroom.
- Her family make an appointment with their local GP to discuss what has been happening. The GP says that there are some developmental concerns with Sophia and recommends that they get an assessment with a specialist.
- Sophia's family is unable to afford a private assessment. They join a waitlist for the Child Development service at a public hospital. It takes over a year to see a specialist. During this time Sophia is not eligible for support from the NDIS.
- At the age of 12, Sophia undergoes a multidisciplinary assessment which identified her as having Autism level 2. The hospital suggests they apply to the NDIS when they go home. As Autism levels 2 and 3 are included in List A, the report from the hospital with the diagnosis is sufficient to meet access.

Future access pathway

- Sophia's school raises concerns with her family.
- The school suggests they speak to a local Navigator to understand what support may be available for Sophia and the family.
- The family are anxious talking about their daughter with someone they do not know. They agree to have a phone call with a Navigator in a few days' time. Sophia's family tells the Navigator about her experience, what the school had told them and that their GP had previously mentioned that she may have developmental concerns.
- The Navigator explains what foundational supports are and gives Sophia's parents options for peer-support and family capacity building. Some are online, others are in-person. They

- are a little unsure but the Navigator suggests to try two sessions and then decide whether they like it.
- Noticing that her parents are very interested in supports directly for Sophia, the Navigator also suggests a small number of online peer-support programs where Sophia can meet other girls of the same age who share similar interests and further develop her social skills.
- The Navigator identifies that Sophia's brothers will need some support too, but decides to wait until the parents have begun to attend the peer-support sessions, thinking this idea will make more sense to the family once they have begun to talk to other families. The Navigator sets a reminder to check-in in one month and to give some ideas for the brothers then.
- The Navigator explains what the NDIS is and what support could be available. The Navigator suggests speaking to their GP about their experiences with Sophia. The Navigator explains that it could be good to get a diagnosis to help understand Sophia's experience, but that the family does not need to wait for it to get help from the NDIS.
- The GP says that there are some developmental concerns and encourages the family to seek additional support for Sophia to assist her with some of the issues she is experiencing at school.
- Sophia's parents meet with the Navigator in person this time and relay what their GP has said. The Navigator shows them the Access Request Form and explains how to begin making a request so that they can share the link with their GP to populate the treating professional section.
- Once the parents complete and submit the initial section of the access request (with additional information added by their GP), they receive feedback that Sophia is eligible for a needs assessment. They are told this is required to understand whether Sophia needs extra support from the NDIS. If she does, the needs assessment will also be used to set Sophia's NDIS budget.
- Sophia is matched to a skilled NDIA Needs Assessor who is an occupational therapist experienced in working with young people. The assessment reveals that Sophia's needs are very high compared to her peers and higher than her school had suggested.
- Based on Sophia's age and need level, the NDIA agree that she is likely to benefit from early intervention support that includes assistance with emotion regulation, communication and social skills.
- Sophia and her family continue with the foundational supports while they begin to work out how to use Sophia's NDIS budget with help from their Navigator – who has been assisting since the start.
- Sophia has been receiving supports for over a year by the time she receives a diagnosis from the regional multidisciplinary assessment team. The diagnosis does not impact the level of support she receives from the NDIS, but helps Sophia and her family better understand her support needs.

Case study 6: Viktor, 60 years old, male, brain injury, section 24 (disability requirements) access request

Viktor has a history of traumatic brain injury. His family have recently noticed changes to his behaviour and are concerned that he is experiencing memory loss.

Viktor's wife, Anna, is concerned that he hasn't been himself lately. He is really struggling to remember his schedule and how to get around the house. Anna is doing a lot more for Viktor than she used to. He has lost his independence.

Current access pathway

- Viktor and Anna visit their GP who conducts a cognitive screening test (GPCOG), takes blood tests and reviews his current medication use to rule out other issues. The GP also refers Viktor for a CT scan. After receiving the results of the tests, Viktor's GP refers him for an assessment at the memory clinic at the local hospital.
- Viktor has to wait four months to get an appointment. At the memory clinic, a team of health professionals complete an assessment. Viktor is diagnosed with early-onset dementia and the memory clinic staff suggest that he may be eligible for NDIS. When Anna asks what needs to happen next the memory clinic staff member doesn't know and suggests giving the NDIA a call. They look up the NDIA's number on the clinic's computer for Anna.
- Anna calls the NDIA and asks about access. The NDIA call centre tells Anna they will mail a paper version of the Access Request Form.
- When the Access Request Form arrives, Viktor and Anna are not sure what information he needs to provide. They have a letter from the memory clinic which describes his Viktor's diagnosis which Anna makes a copy of. Assuming this enough, they return the Access Request Form to the NDIA.
- Viktor receives a letter three weeks later advising him that he is not eligible for NDIS support. The letter includes legal phrases and jargon. The family does not understand why the letter from the memory clinic was insufficient.
- Anna finds out about Dementia Australia then calls them for advice. They suggest Viktor provides additional evidence of how dementia is impacting his life and to request an internal review. They also suggest getting a report from someone familiar with the NDIA requirements.
- Anna finds a local occupational therapist who tells Viktor they can write a report for him that will meet the NDIA requirements. The family will have to pay out of pocket for the functional assessment and report. This costs Viktor and Anna $3,000 dollars and he receives a 50-page document from the occupational therapist three weeks later.
- Anna re-submits Viktor's evidence with the new report that includes the right phrases about a substantial loss of functional capacity and is found eligible upon review.

- After receiving the diagnosis from the memory clinic, the clinic staff suggest Viktor should consider applying for NDIS and tell them to either call the NDIA or connect with the local Navigator.
- Anna calls the NDIA to ask about getting access. The NDIA tells Anna that they can mail the Access Request Form to her, but if they would prefer in-person help there is a local Navigator in their town who they can visit.
- Anna likes the idea of Viktor talking to someone face to face so they drop-in to their local Navigator office the next morning without an appointment.
- The Navigator reads the report from the memory clinic and hears about Viktor's experience. The Navigator explains more about what the NDIS is and what support could be available.
- The Navigator helps Viktor and Anna enter the initial information into an Access Request Form and to upload a copy of the report from the memory clinic. The Navigator explains that the report would not be enough on its own to get access, but it will help get to the next stage.
- The NDIA responds within a week and approves Viktor for a functional assessment. They provide a list of locally based specialists who are NDIS-approved. Because Viktor and Anna live in a regional town, there are only two potential choices they can easily drive to. Viktor has heard of one before and chooses them. He makes an appointment.
- Viktor completes the functional assessment two weeks later and is surprised to find out he doesn't have to pay for it. The specialist tells Viktor that they need to finish writing up the results of the assessment but that they'll send through a copy directly to the NDIA and a copy to him by the end of the day. They tell Viktor that he has substantially reduced functional capacity in the cognitive domain.
- When Viktor and Anna return to see the Navigator the next day, the results of the functional assessment have already been processed by the NDIA (as the assessment is linked to the access portal). They are very happy to find out Viktor has been granted access to the NDIS.
- Viktor's Navigator talks to him about the next step of a needs assessment and schedules him for an appointment.

2.1.4. Action & Implementation Details

Action 3.1: The National Disability Insurance Agency should introduce a more consistent and robust approach to determining eligibility for access to the NDIS based on transparent methods for assessing functional capacity.

This should include an agreed definition of substantially reduced functional capacity to give more clarity to applicants and consistency in decision-making. This definition should be linked to the outputs of a functional assessment process that can measure the impact of impairment and allow applicants to be compared to their peers (norm-referenced

assessments). The definition could then be operationalised through measuring standard deviations from the mean.

Existing functional capacity assessments should be transparently tested with the groups and disability types they have been validated for to inform the design of the new access process. Where appropriate functional capacity assessment instruments do not exist or are not fit for this specific purpose, these should be designed and validated with the groups for whom they will be used. This should build on existing work that has already established a clear need for a new assessment of functioning for some groups and disability types.

Any assessment should cover a broad range of domains in order to be strongly considered for use (e.g. cognitive, language, social-emotional, motor and adaptive behaviour). There should be an accepted basis for comparing results from two or more acceptable instruments that might be used to assess function in a given domain. Any assessment considered should take into account that disability can fluctuate over time, and based on the environments in which a person is in. The assessment should be able to be undertaken by the applicant's treating professional and should be funded by government. Additional evidence required by the National Disability Insurance Agency to inform complex access decisions should also be funded by government.

Once a participant has met access requirements through the new approach, following a functional capacity assessment, they would not be required to be reassessed unless there are exceptional circumstances.

Existing access lists should be removed and automatic access replaced with streamlined evidence requirements to ensure only essential information is collected for all people seeking access. These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8).

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should design and test an assessment process to determine functional capacity for the purpose of informing access decisions. This assessment process should have the following features:

  - Apply only to individuals where the functional impact of the impairment(s) cannot be determined through an alternative form of evidence, such as a diagnosis that indicates the threshold level of impairment for eligibility has been met

  - Be a customised functional assessment(s) fit for the purpose it is being used, based on existing validated functional capacity assessment instruments. This may be a suite of assessments tailored to particular needs, or it may be a single, responsive process

  - The assessment(s) should be designed through a transparent process that begins with testing existing validated assessments for this specific use. The design process must include (but not be limited to) participants and applicants, representative

organisations, functional measurement experts and researchers, and health professionals

- The assessment(s) should:

  o Be norm-referenced to measure functional capacity in a way that allows applicants to be compared to their peers
  o Collect the minimum evidence on level of impairment and permanence of that impairment to satisfy a delegate that requirements have been met
  o Map to the World Health Organisation International Classification of Functioning, Disability and Health to enable consistency of data collection and tracking of outcomes across service systems
  o Be able to be undertaken by an applicant's treating professional provided they have been trained and approved to use the validated assessment instrument. An applicant could also choose an alternate assessor, or an assessor sourced by the NDIA if needed. In any scenario, the cost of the assessment should be met by government (ideally through Medicare)
  o Be designed with and acceptable to the people and groups it is used to assess.

- There should be a mechanism for monitoring the assessments undertaken by treating professionals. Monitoring should identify trends, and help to identify if there are concerns with the way assessments are being carried. Further investigation could lead to appropriate action, including barring individuals from completing further assessments for the purpose of providing evidence to the NDIS

- In limited circumstances where a decision about eligibility may be more difficult because of the complexity of the disability, interactions with health conditions, and / or the characteristics of the applicant's circumstances, the NDIA may request additional evidence (including an additional functional assessment by another independent professional) at the cost of Government. The information collected would then be reviewed by an NDIA appointed panel which includes an NDIA chair and delegate, as well as individuals independent from the NDIA with clinical and disability expertise (including lived experience). The scenarios in which this variation would be permitted by the NDIA, and the process of having the information reviewed by the panel, would be included in the NDIS Rules for transparency

- The NDIA should begin implementation of the assessment process once Disability Reform Ministers have endorsed the assessment process and proposed implementation approach.

• The National Disability Insurance Agency should develop an agreed definition of substantially reduced functional capacity that can be linked to the assessment process described above. This definition should be brought to Disability Reform Ministers for consideration and approval prior to implementation, and to be included in NDIS Rules.

- The NDIS Experience Design Office (see Action 24.3) should develop and publish an objective methodology to determine what evidence enables streamlined access where it can provide a strong indication of permanency and substantially reduced functional capacity, without the need for a separate functional assessment.

Action 3.2: The National Disability Insurance Agency should introduce a new Access Request and Supporting Evidence form and accompanying guidance to make the process of applying for NDIS access more transparent and simple.

This should include a new, dynamic online form. The form and guidance should update as details are entered by the applicant, nominee or treating professional, making it clearer what information is required and why. It should also give real-time guidance where additional evidence is needed or there are issues with information entered. This should offer a more guided experience for applicants and allow for evidence from the applicant as experts in their own lives and needs, alongside evidence from treating professionals. There should also be additional guidance for treating professionals on what evidence is required and why, to improve the consistency of evidence and equity of access outcomes. This should be in addition to enhancements to existing verbal or printed access request options to give applicants more choice in how they apply for NDIS access.

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should design, test and introduce an online Access Request Form (inclusive of what are formerly Supporting Evidence Forms) that includes the following features:

  - Guided, responsive questions that enable an applicant, representative or treating professional to provide information for an access request in a streamlined way.

  - Applicants and representatives receive clear explanations of what questions mean and can provide basic information about themselves, their needs and their developmental delay or disability in a way that suits them.

  - Dynamic form that adjusts depending on the applicants' communication requirements, language, personal circumstances, applicable access pathway and evidence requirements.

  - Treating professionals can submit consistent evidence with clear expectations and guidance on what specific information is required and what NDIS and NDIA terminology means.

- - Linkage to existing data from other service systems, including MyGov and MyHealth Record, with the applicant's consent and final approval to remove the need to provide information twice.

  - Transparency of data so applicants and representatives can view and easily access the information they have provided or was provided by a treating professional.

  - Visibility of progress through the application process so applicants and representatives can see what stage their access request is at and professionals can see feedback when further information or clarification is required.

- The NDIS Experience Design Office (see Action 24.3) should design, test and introduce enhancements to the existing verbal and paper-based Access Request Form and Supporting Evidence Forms, including the following features:

  - Detailed prompts for NDIA staff taking verbal access requests to tailor questions based on an applicant's responses, reflecting adjustments from the dynamic form.

  - Revised sequencing of questions included in the paper-based form to fast-track applicants to the most relevant questions based on their responses.

- The NDIS Experience Design Office (see Action 24.3) should design, test and introduce revised guidance for applicants, representatives and treating professionals completing Access Requests or providing supporting evidence, including the following features:

  - Integrated guidance with questions on the access request form.

  - Explanation of what a question means, definition of key terms, and what information is expected in response.

  - Guidance offered in fully accessible and inclusive formats, including translated, Easy Read and other formats that meet complex communication support needs.

  - Guidance that can be used by Navigators (see Action 4.1) for applicants who require support to submit an Access Request.

Note: Action 3.8 applies to all reforms across the participant pathway. It has been included earlier in the chapter for this reason. It applies to all proposed changes to the pathway.

Action 3.8: The National Disability Insurance Agency should implement reforms to the participant pathway using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

Reforms to the pathway (see Actions 3.1 to 3.7) should be designed through agile projects commissioned by the NDIS Experience Design Office (see Action 24.3). Design, testing and implementation should be undertaken with people with disability and should be aligned with

the principles and implementation considerations set out in the *Co-Group Feedback to the NDIS Review Panel*, developed as part of the Review's participatory engagement process (for further details on the Co-Group's work see Appendix B), as well as the Australian Government Digital Service Standard. Inclusive and proportional user testing should be conducted to allow priority reforms to be phased in and start delivering benefits as soon as they are validated and approved by Disability Reform Ministers for implementation. Assessment processes in particular require highly transparent, rigorous and inclusive design and testing prior to implementation. Implementation of the changes to the pathway should adhere to a principle that ensure all current participants experience a smooth and fair transition to the new arrangements (see Action 26.2).

Implementation detail:

- The Australian Government should ensure the NDIS Experience Design Office is appropriately resourced and funded to attract appropriate expertise and experience to deliver on its scope of work, including but not limited to:

  - Capability to commission and deliver an extensive program of iterative design and testing, including expertise in agile delivery, experience design, prototyping and product development, service design, user research, business analysis, commissioning and service delivery

  - Significant lived experience representation within teams, management and the executive

  - Technical expertise in functional assessments, developmental assessments, needs assessments, measurement and early intervention. This should include individuals with frontline assessment experience.

- Once the NDIS Experience Design Office has been established, reforms to the participant pathway should be designed with consideration of the following:

  - Improvements to the process of making an access request (see Action 3.2) should be prioritised to deliver a more streamlined access process sooner. Improvements should not be delayed until the assessment(s) or other reforms are ready for implementation

  - The assessments should be designed through a transparent process that involves extensive testing of existing validated assessment instruments and any subsequently modified or developed assessments and processes. The design process must include (but not be limited to) participants and applicants, functional measurement experts, health professionals, and representative organisations

  - It is envisaged that the needs assessment (see Action 3.4) could be first implemented as an information gathering process within the existing planning pathway (without it being directly linked to budget setting). This would provide for a smoother transition between the current pathway and the proposed future pathway. It would also allow

for wider testing of the assessment and building broader familiarity with the assessment before the new approach to budget setting is implemented.

- When pathway reforms are being implemented, the NDIA should ensure that all participants receive a smooth transition to the arrangements. This includes any participants who would otherwise experience a significant change to their funding arrangements during their first needs assessment (see Action 26.2).

Action 3.9: The Australian Government should update and clarify legislation to support a more effective approach to determining access

This should include updating the *National Disability Insurance Scheme Act 2013* and NDIS Rules to support the implementation of the changes described in Actions 3.1, 3.2 and 3.7. This should also consider the need for legislative changes to strengthen the operation of the permanence criteria while ensuring availability and affordability of supports for people with disability outside the NDIS (following the Federal Court decision known as National Disability Insurance Agency v Davis).

Implementation detail:

- The Department of Social Services should consider the need for legislative changes to strengthen the operation of the permanence criteria in section 24(1)(b) of the NDIS Act and in the NDIS Rules while ensuring that treatment for people with disability outside the NDIS likely to be affected by the change is available and affordable (following the Federal Court decision known as National Disability Insurance Agency v Davis). This process should include extensive engagement with people with disability and representative organisations, as well as administrative law experts.
- The Department of Social Services should develop and bring forward proposed amendments to the NDIS Act and Rules to enable the implementation of the proposed changes described in Actions 3.1, 3.2 and 3.7. Amendments should be developed once the assessment process and agreed definition of substantially reduced functional capacity have been appropriately designed as set out in Action 3.8.

2.2. There should be increased investment in getting the budget right for each participant and more support to use a budget

Having a nationally consistent approach to the funding of reasonable and necessary supports for participants is a core objective of the NDIS. This means that funding decisions should be fair and consistent - participants with broadly similar levels of need and circumstance should receive

broadly similar budgets. To ensure that participants can choose supports that best meet their needs, there should also be greater flexibility in how allocated funds can be spent.

We have been told that the current planning processes are at best confusing and frustrating and at worst stressful and traumatic for participants and families. It is not always clear to participants how evidence is assessed, how or why decisions are made, or how budgets are calculated. This in turn makes it difficult for participants to know exactly how funding can be used.

A lack of clarity about reasonable and necessary is at the heart of many of the issues with planning. Reasonable and necessary is the source of much tension and conflict during planning and review processes, and has lead the NDIA to impose ever-increasing demands for costly evidence, reports and process tasks before a support is approved.

Participants have also told us about the many administrative barriers that then stand in the way of using their allocated funds in a way that works for them. They have told us that the language of plans and rules that limit the use of funds are confusing and complex. There is no consistent support to help participants make the most of the funding they have received.

The future approach to budget setting should be fair, transparent, equitable and consistently needs-based. This should include the process for determining a budget through to how that budget can be used flexibly to meet individual need. We are proposing a package of reforms to improve the experience of budget setting for all participants and ensure that participants are supported and enabled to exercise real control and choice when using their budgets.

These proposed reforms have a strong intersection with the support provided to participants to implement their budget. This is covered in detail in Section 2.2.2. These reforms are also closely linked to a revised approach to budget setting for children under the age of 9 and support for children and families to use their budgets. The details of those reforms are set out in Section 5.4.3.

2.2.1.   The current approach to setting and implementing plans is adversarial and inequitable and there is little flexibility or support to use plans

The current approach to developing plans, how participants may (or may not) use allocated funds, and the variable, fragmented or non-existent ways they are supported to implement their plans have failed many participants. This has shown the NDIS as neither person-centred nor consistently needs-based.

NDIS funding for a participant is determined by the legislated concept of 'reasonable and necessary'. The concept was intended to ensure the NDIS could be responsive to individual need and circumstance. But 'reasonable and necessary' in the NDIS is a broad, imprecise and, at times, idiosyncratic discretionary concept that leads to tension and conflict during planning and reviews. At the same time, 'reasonable and necessary' has become difficult to explain or administer fairly, consistently and equitably.

The broad spectrum of NDIA decisions about which individual support may (or may not) be considered reasonable and necessary is inconsistent and, at times, contradictory. Lack of a shared

understanding of reasonable and necessary can also lead to conflict between participants and the NDIA about what supports the scheme should be expected to deliver.

The planning is described by participants as adversarial and judgemental. Participants and their families feel they are not believed when they try to describe their needs and circumstances. The confrontational nature of the meetings has created an unhelpful cycle. When people feel they are not trusted, it is difficult for them to believe support will be there for them when they need it or when circumstances change.

Participants and their families believe (often correctly) they must present their 'worst self on their worst day' to make a stronger case for the supports they need and a 'reasonable and necessary budget'.

Individual support types in particular have become contested areas. They may be approved (or not) based not on the need for support, but on the relative confidence, skill and ability of the individual or their family and supporters to advocate, seek remedies and collect evidence.

Once participants receive a plan, many struggle to understand the structure and language, how allocated funding may be used, or what the spending rules are. In a scheme in which a large proportion of participants could benefit from supported decision-making, many have no access to support to help them make the most of their funding to meet their needs. Plans are complicated documents that offer limited guidance on how to use the budgets. Participants told us they often receive conflicting advice from the NDIA and their Partners in the Community about how their funds should be used.

Receiving and implementing a plan has become characterised by complexity and a lack of mutual trust between the NDIA and participants. A re-set is desperately needed.

The current planning process

Planning processes are currently used to simultaneously develop goals, create a plan to achieve identified goals and set funding to match goals and need.

Participants need to provide significant evidence to inform planning processes, including reports and assessments from treating health professionals. Participants must often start gathering evidence months ahead of the anticipated planning meeting to have sufficient time. As part of the reports provided to the NDIA, allied health professionals often outline goals they believe are appropriate for the participant and make recommendations on the specific types of support and associated number of hours to be included in a plan.

To be confident in planning processes, participants and their families need to know what to expect from the process, and what information they need to provide to ensure a complete picture of their needs and circumstance.

The uncertainty of what planning entails is highly stressful for participants and families. The NDIA currently provides a booklet that includes information about how to get ready for a planning conversation. There are also a range of other resources and information that have been developed by representative organisations to support participants in thinking about and preparing for their

planning meetings. While these resources can be helpful they are often general in nature. This leaves participants to try to tailor preparation to their own circumstances.

Participants and their nominees attend a planning meeting with a Partner in the Community or NDIA planner to begin developing or reviewing their plan. This can happen either in person, over the phone or via videoconference. While participants are supposed to have a choice between those options, we have heard this does not happen consistently for all participants. There is also the confusion on whether a participant has agreed to a plan rollover instead of a plan review. We have heard that short phone calls from the NDIA have led to plan rollovers occurring without the participant understanding whether authorisation was provided. These issues are then only uncovered when service bookings are cancelled or claims are rejected at a later stage.

The Partner in the Community or NDIA planner uses guided planning questions to understand functional capacity, circumstance, informal supports and goals for the participants. How the guided planning questions are used to understand participant goals and aspirations and required supports varies significantly. Some participants will have undertaken a functional capacity assessment externally and some will be asked functional capacity assessment questions as part of information gathering.

The Partner in the Community or NDIA planner then needs to identify reasonable and necessary supports that will assist the participant in meeting their goals and needs, including what supports have been requested by the participant and in any evidence from treating professionals. The individual supports will be built up into one of the three types of support budgets that may be funded as part of the plan: Core Supports budget; Capacity Building Supports budget; and Capital Supports budget.

The plan will then be sent to the NDIA delegate without the participant or their family member seeing a draft of what has been prepared.

An NDIA delegate will determine whether each of the supports items in these categories are reasonable and necessary and make a decision to approve or not approve the supports. Most participants never meet the delegate who makes the ultimate funding decision. This is particularly challenging for participants who complete the initial information submission stage with a Partner in the Community who is outside the NDIA and has no delegation authority.

In making a decision about a support being reasonable and necessary, the delegate must consider a significant number of factors within a highly complex policy and legislative framework. Figure 34 illustrates this process at a high-level. Figure 36 illustrates the complexity of the policy, legislative and operational framework for a decision maker.

The delegate will also compare the potential support budget generated by the planner against an automated benchmark reference package, adjusted for age, disability type and level of function, known as a Typical Support Package. Figure 38 provides more detail on Typical Support Packages.

This benchmark gives guidance to the delegate on the amount of funding that may be needed for the participant based on information captured during planning and entered into the NDIA Customer Relationship Management system.

The approved plan will then be sent to the participant without them seeing a draft.

Figure 34: High level overview of the planning process
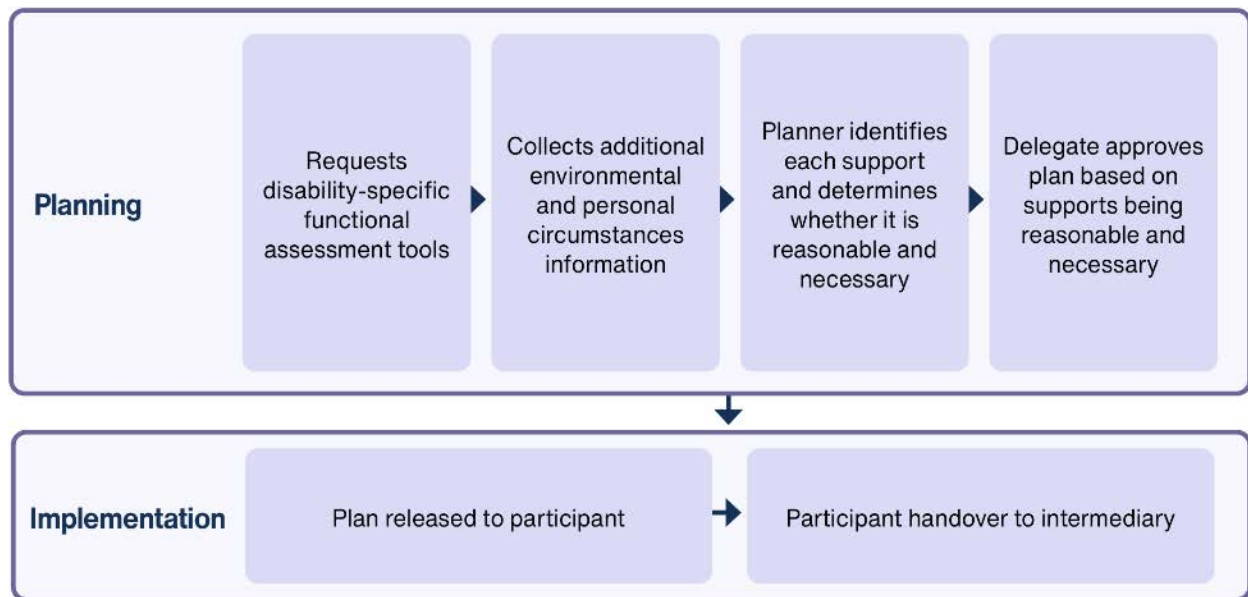
The current approach to plan implementation

A plan that is sent to participants is a long document (Figure 35). It must include the overall funding amount and includes a breakdown of funding for each of the Core, Capacity Building and Capital Supports budget, any specific stated supports included, supports that may require a quote or further evidence, and information on supports which are provided 'in-kind'. It also includes the participant's statement of goals and aspirations (see Box 15). These are specific requirements under the NDIS Act of what needs to be included in a plan.

Figure 35: Example plan gives an indication of the length and inclusions of the document

> **Box 15: Experiences of participant's statement of goals and aspirations in a plan**
>
> We have heard that the statement of goals and aspirations are frequently out of date. They are often cut and pasted from a previous plan. Sometimes they are still being rolled over from the very first plan many years later.
>
> We have heard that the 'about me' section in a plan is not typically created by the participant despite it being written in first-person language. There have also been glaring errors in this section. Plans have been finalised and approved with descriptions of the participant that include the wrong names, ages, support needs, interests and locations. They are particularly glaring errors when they don't align with the supports approved by the delegate on the following pages of the plan. Suggesting little or any time was spent on the first sections of the plan about the participant. This is highly 'cookie cutter' approach to planning.

Participants have to navigate how to utilise funding within the opaque constraints of different funding categories and line items. Each of the three support category budgets has additional sub-budgets for particular support sub-categories which may also have constraints around them. There are fourteen different sub-categories in total and different rules apply to how each of these funding allocations can be used. Having funding split into so many categories creates complexity. The rules which govern allocations are not clear or always known. This limits participant choice and control. It is also rarely made clear to participants how each of the sub categories were calculated, so they cannot understand the assumptions the planner used.

During the trial of the NDIS, participants were given some assistance by NDIA staff to understand and implement their plan. This function was largely transferred to Partners in Community once transition to full scheme began. However the large volume of participants and plans required during the transition years meant the focus for Partners in Community quickly shifted - and has stayed - with creating and reviewing plans.[583]

There was also an expectation that Support Coordinators would fill the gap for many participants. However, not all participants are funded for Support Coordination and those without the support are reliant on informal supports to identify what supports or providers to use and how to coordinate these supports.

Similarly, Plan Managers are rarely funded to support participants to self-direct their funding. Instead Plan Managers have become predominately focused on performing administrative tasks – such as, processing invoices and paying providers on participants' behalf. Support currently provided by Plan Managers to monitor spending and managing funding is highly variable.

Key issues with these processes and approaches

The key issues with the current approach can be considered in terms of:

1) How plans are set and reviewed	• Including challenges resulting from a lack of clarity around reasonable and necessary.
2) How participants are allowed and supported to implement their plans	• Including the complexity and inflexibility of plans and the level of support for participants to get the most from their funding.

Setting and reviewing plans

The challenge of the concept of reasonable and necessary

Reasonable and necessary was intended to be a core concept of the NDIS that distinguishes the scheme as a nationally consistent needs-based system from preceding state and territory based systems frequently subject to arbitrary rationing of condition-specific supports (see Box 16).

Reasonable and necessary was initially intended to serve two purposes:

• To oblige the NDIS to provide a level of support to a participant to meet need.
• To define the level of support that is provided to a participant.

These interdependent purposes sought to meet individualised disability-related support needs within a financially sustainable NDIS that could ensure lifetime supports to generations of Australians.

> **Box 16: Productivity Commission Report 2011 – the basis for providing disability supports**
>
> 'A key point of distinction between existing arrangements and those proposed under an NDIS would be the obligation for the scheme to deliver the package determined by the independent assessment of need, rather than the present arbitrarily rationed amount. This feature is an essential element of avoiding the chronic underfunding that has beset the current disability system. However, that does not mean that the provision of supports will be unconstrained. Indeed, in other, better resourced schemes — such as no-fault accident insurance schemes that provide lifetime care and support for catastrophic injuries — service provision is 'bounded' by the concept of reasonable and necessary.'[584]

Reasonable and necessary within the NDIS is therefore intentionally bounded, while also being a broad and flexible concept to ensure support can be tailored to the unique needs of individuals. However, without an adequate framework for understanding and applying reasonable and necessary consistently within the NDIA, the intended benefits of flexibility within overall budgets have been lost.

Inconsistent interpretation of what reasonable and necessary means has created uncertainty for participants and planners about what supports could be funded. That uncertainty has driven upward pressure on costly evidence and reports to justify specific types of supports. Reviews have become adversarial arenas in which evidence (or its absence) is contested participant by participant, plan by plan and in some cases line by line of a plan.

Across the whole scheme, a lack of shared understanding, inconsistency and uncertainty has resulted in significant frustration, stress, conflict and trauma.

> [Reasonable and necessary can lead to] *"...highly discretionary decision-making where decision makers seek to balance incommensurable values such as choice and control, goals and aspirations, value for money and financial sustainability, and research evidence base vs lived experience of benefit. These are tensions built into the NDIS legislative scheme from its fruition which complicate the operationalisation of decision-making." – Griffith University* [585]

That challenge has been compounded by the requirement under section 34 of the NDIS Act that each support must be determined to be reasonable and necessary to be funded. This means the issue of managing the flexibility and uncertainty of reasonable and necessary can play out for every single support item for a participant and planner. The result is inconsistent decisions and funding outcomes.

> *"...the other language that people found very, very distressing was around value for money, like getting a plan back that says, 'this is not value for money' and that was something that [would have] had a really big impact on that person and their family. – Anonymous* [586]

There is a highly complex legislative, policy and operational framework that decision-makers and participants must wade through in their attempts to understand and apply reasonable and necessary (Figure 36). Given the degree of complexity it is not surprising that, ten years in, there is so much inconsistency and so many gaps in expectations that arise due to reasonable and necessary.

We heard that some participants would be more comfortable with limits on the kinds of supports that are funded as long as it was clear what those limits were.[587] Participants and families are particularly frustrated by the expectation gap created by not knowing what is likely to be funded, being told to seek evidence to justify need, and then having a request rejected without clear communication of the reasons. Greater clarity from the outset would reduce much of this frustration and contest.

Figure 36: Legislative, policy and operational framework for reasonable and necessary[588]

NDIS Act – Relevant Objects:

- Support the independence and social and economic participation of people with disability
- Provide reasonable and necessary supports, including early intervention supports, for participants
- Enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports
- Facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability
- Promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community

NDIS Act – Section 34: Reasonable and Necessary

Each support must satisfy criteria to prove that it is reasonable and necessary, including that each such support:

- Will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations
- Will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation
- Represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support
- Will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice
- The funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide
- Is most appropriately funded or provided through the NDIS, and is not more appropriately funded or provided through other general systems of service delivery or support services

NDIS Rules – Supports for Participant

- Prescribe methods or criteria to be applied, or matters to which the CEO is to have regards, in deciding whether to approve supports under section 34.
- Additional requirements set out how to assess whether a proposed support will be value for money, or is likely to be effective and beneficial

CEO Direction

NDIA Operational Guidelines – Reasonable and Necessary

- The Operational Guidelines are intended to assist NDIA delegates to appropriately perform or exercise their functions and powers in making decisions.
- The reasonable and necessary operational guidelines ensure supports are related to the individual's disability, have value for money, are effective and beneficial, and are most appropriately funded or provided by the NDIA

NDIA Practice Guides

NDIA Standard Operating Procedures

How the NDIA has responded to the challenge of defining reasonable and necessary

Making decisions about what supports are reasonable and necessary for hundreds of thousands of people with disability is a complex operational undertaking. The NDIA can make thousands of decisions a week. This is an enormous number of complex decisions for any service system to manage. It is particularly challenging in a scheme that serves a population with such diverse needs and circumstances as the NDIS.

The number of applications to the Administrative Appeals Tribunal (AAT) is a good indicator of the issues the NDIA have making good consistent decisions that are understandable for participants.

Pressure on decision-makers in their role was most evident following the introduction of the Participant Service Guarantee (PSG). This period coincided with a significant increase in the number of applications to the AAT, suggesting that the quality of decision-making was impacted by the timeframes established in the PSG. It can be assumed that this pressure created a dual issue whereby complex decisions also needed to be made more quickly than before, with no discernible increase in staff resources at the NDIA.

The increased number of applications to the AAT was also driven by the number of plan reductions. Approximately 105,000 plan reviews resulted in a 5 per cent or more reduction during the financial year July 2021 to June 2022[589] (equivalent to approximately 26,000 each quarter). In comparison, there have been 43,000 plan reviews with a 5 per cent or more reduction in the nine months from July 2022 to March 2023[590] (equivalent to approximately 14,000 each quarter).

In short, the higher number of participants impacted by a plan reduction will have resulted in higher numbers of applications to AAT. This suggests a combination of factors led to increased AAT applications during this period.

> *"What caused the disturbingly large AAT back-log of cases in the first place, and their subsequent rapid resolution (without proceeding to AAT) can only be explained by changes in the practices/processes of the Agency itself." – Independent Expert Reviewers [591]*

Figure 37: Number and proportion of new AAT cases over time[592] (timing of PSG changes overlaid)[593]
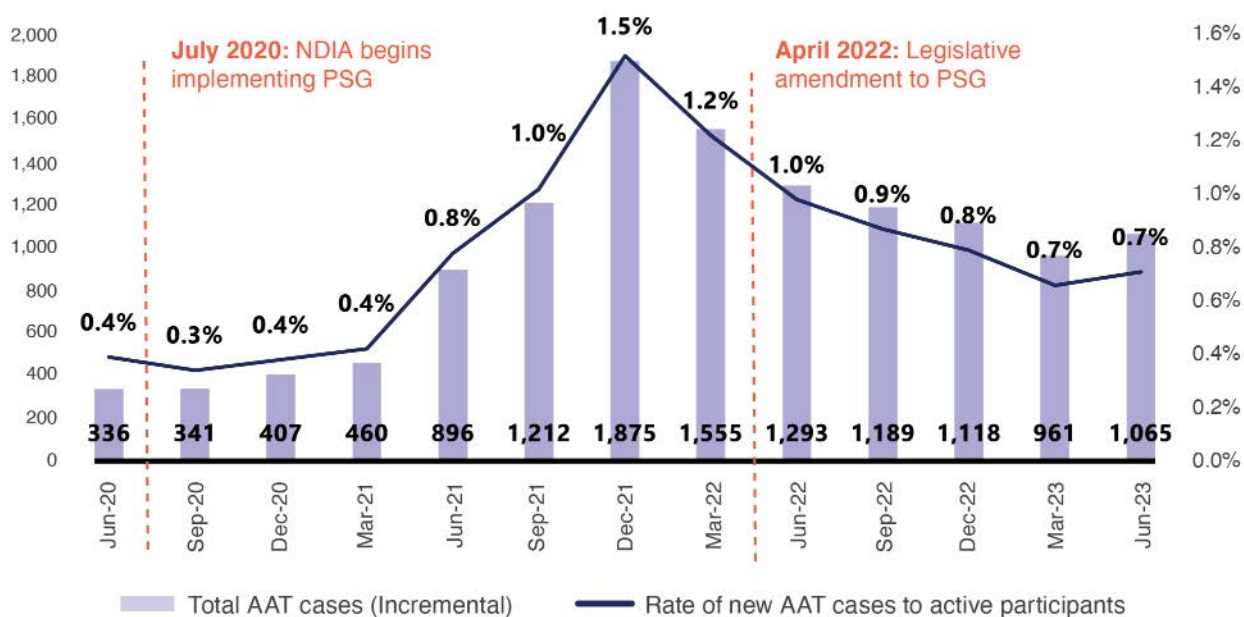
Making complex decisions quickly is a particular challenge for the current workforce. Making decisions about multiple types and volumes of support that interact with each other requires "well-informed and well-trained staff... [who can] understand the complexities and nuances of individual needs and appropriate individualised supports".[594] We have heard from participants, planners and allied health professionals alike that the ability to understand the supports that a participant needs requires a specific skillset, significant training, and in many cases allied health experience and qualifications (or similar). Very few planners hold this level of expertise.

> *"Training goes over a few weeks. You're basically sitting in teams meetings for the duration, and you're getting told information that doesn't make any sense to you. It would be useful to have an introduction week, and a buddy system or smaller group meetings where you go through actual cases..." – Planner [595]*

> *"I always feel like I'm taking a bit of a wild stab in the dark when it comes to funding therapies... I guess it's hard to write procedures that are good for everyone, especially given the different ways that the same disability might affect different people." – Planner [596]*

Planners without these qualifications or limited (sometimes no) disability-specific training or experience are being required to make thousands of critical decisions that profoundly impact the lives of participants. This can also be with little or no face-to-face contact with a participant.

They are asked to consider recommendations included in reports provided by allied health professionals who have completed often lengthy assessments with the participant. Planners have to consider the recommendations from a trained and qualified professional without completing their

own assessment of the participant. At the same time the assessments available to planners focus on function rather than support need and may not provide a good basis for determining need, nor provide a good comparison with the much more detailed information provided in a report from a participant.

A planner who does not accept a recommendation from an allied health professional when considering a budget is likely to cause significant confusion and distress for a participant – who has been told by a trained and qualified professional that a specific type and level of support is required.

> *"Even when a support is recommended by multiple professionals NDIA still chose not to fund it." – Participant* [597]

Often planners are restricted by the NDIA and its systems to focus on a limiting concept of a primary disability (which has only been maintained due to limitations of NDIA technology). Evidence that does not strictly relate to the 'primary disability' diagnosis in the NDIA system is often not used. This is because supports will not be funded under the NDIS if it is not related to the participant's disability. The NDIA appears to take the view that a participant's disability is the specific diagnosis or impairment that access to the NDIS was granted for. This is confusing for participants with multiple disabilities who justifiably understand their needs more holistically and expect the same from the NDIS.

Those limitations become even more confusing where the NDIA does not provide clear explanations for decisions it takes. Often the NDIA relies on legalistic language, broad references to elements of the legislation and its own obscure planning terminology. These communication and language barriers are commonplace. They create significant frustration for participants and erode trust in the NDIS.

> *"We don't really get training around trauma informed or complex communication needs. Once had to talk to someone with psychosocial disability and didn't know about things they needed. Participants going into palliative care it's more complicated. It would be good if we had more training around that." – Planner* [598]

> *"In my experience, planners have not wanted to know how my disability affects my everyday life." – Participant* [599]

Previous reviews have made findings on the issues of inconsistency and inequity of funding decisions by the NDIA and the impact these decisions may have on participants' quality of life.[600] The Joint Standing Committee has repeatedly heard evidence on major inconsistencies in funding decisions, including examples of siblings with the same disability type receiving inexplicably different funding decisions.[601]

Submissions to this Review add to the already extensive evidence of both inconsistency in individual funding decisions and inequity across the scheme.[602] Issues with planning and the inconsistency of decision-making were the most commonly raised issues in submissions. This

inconsistency is driven by a planning process that relies on the judgement of planners, who do not receive sufficient support to make the volume or type of decisions they are required to make.

> *"NDIS is not consistent with decisions... saying [something] is NOT approved but yet others get it (that need it less)... only because of who made the decision on the day at NDIA" – Participant [603]*

> *"Feeling like it depends on the planner and their personality rather than solid processes and procedures as to how my plan might turn out" – Participant [604]*

Despite variations at the individual level, Taylor Fry analysis in 2021 found that 'average plan sizes do not appear to systematically vary for most regions by SEIFA [Socio-Economic Indexes for Areas] score or capital/regional areas'.[605]

The Melbourne Disability Institute found in 2023 that 'participants who live in regional and remote areas receive slightly smaller plans' and 'participants who live in socio-economically disadvantaged areas on average received smaller plans', though 'inequalities were relatively small'.[606] This analysis highlighted that those living in regional and remote areas are more likely to be in a socio-economically disadvantaged area and that arguably those in regional and remote areas require larger plans to receive equitable access to supports as those living in areas where services are more readily available.[607]

The NDIA has responded to the challenge of complex decision-making by requiring greater levels of evidence, increasing the 'burden of proof' on the participant. Participants have raised concerns about the volume, onerous specificity yet breadth and depth of information they are required to gather, often at significant expense. Such demands add to inequities and poor outcomes for some. We have been told that deficiencies in detail (seldom explained), lack of context or insufficiency of evidence can be key reasons for supports being declined for some participants but not others. Some participants have the skills, resources and time to gather the required additional information. Others do not – and may miss out on needed support as a result.

How the information provided is used is not made clear to participants, often resulting in confusion and a loss of trust. For participants that dedicate significant time and resources preparing for planning meetings and reviews, many believe the material they spent so long collating is never read. In some circumstances the NDIA insists that it requires additional evidence from a treating professional but it becomes clear that it may still be ignored and not even read at times by the decision-maker.

> *"Permanent disabilities are permanent, very costly additional reporting stating the same [and] NDIA Planners do not read them" – Participant [608]*

These process deficiencies can also lead to an expensive and time-consuming interim measure when participants do not submit sufficient evidence to satisfy a decision-maker about a particular support. In these circumstances, planners may approve new funding to collect evidence about a declined support to be considered at a future plan review.

This practice becomes visible as plan growth between an early plan and later plans. It contributes to plan inflation figures used to measure scheme sustainability globally.[609] The reality, however, may be that initial plans were underfunded and then grew to a proper needs-based level as participants utilised plan funding to collate the required evidence to correct the initial error in declining support.

> *"If they're saying that, 'Oh, I can't do this, I can't do that, I can't do this,' and we have minimal evidence to actually back that up what I'll say is, 'Well for this plan... we'll put in funding for a capacity assessment to get that evidence. So as soon as you've got evidence... you can put in a change of circumstances." – Planner* [610]

The insistence on evidence from 'professionals' rather than people with disability and their families is both frustrating and deeply disempowering for participants. Many participants report they spend time and money on professional reports that simply confirm what they already know and could adequately describe themselves. The commitment to 'participant as expert in their own life' is undermined by the insistence on professional evidence. There isn't currently a balance between evidence from treating professionals and from participants and families.

This lack of trust in the experience and knowledge of participants and families is also reflected in the way meetings are conducted. As with previous reviews, we have heard planning described as adversarial and confrontational. Many participants describe the meeting as a negotiation with a partner or planner they perceive as trying to limit their budget.

For most participants, planning is a two-step process, beginning when they meet with a Partner in the Community or NDIA planner for their planning meeting. After this, the planner sends the proposed supports and evidence collected to a NDIA delegate, who makes the funding decision. This means that participants usually never meet the person who decides what supports they get. NDIA delegates often make funding decisions without any direct interaction with the participant.

Participants and families also do not have equal access to the information sent to the delegate by the planner. This also means participants and families are not given any access or opportunity to check, amend or approve all information about them sent by the Partner in the Community to the NDIA delegate.

This process gap is disempowering for participants, undermines the legislated principle of choice and control and hampers correct, needs-based decision-making by NDIA delegates. It also places Partners in the Community in the difficult position as mediator between the NDIA and the participant, who is denied their right to fully explain their support needs to the final decision-maker.

These issues compound to create a stressful and traumatising experience. It is telling that so many participants are willing to take up plan roll-overs simply to avoid the process of a plan review.[611]

> *"The next round (of so called planning) we face will be the ninth time in the past year that our daughter's deficits and difficult circumstances will have been trawled through in detail in order to seek reasonable and necessary supports for her" – Carer* [612]

For participants entering under early intervention requirements through section 25 of the NDIS Act, there is also scant operational guidance developed by the NDIA to assist participants or planners to understand the purpose of early intervention, which would inform the shape and quality of early intervention plans. Funding approaches are not differentiated for participants entering under early intervention (outside of the early childhood approach). Rather than timely and targeted outcomes and evidence-based interventions, an individualised plan is created as it is for all other participants.

Efforts to improve the processes

NDIA has made significant effort to improve the consistency of the current planning process since the beginning of the transition period despite considerable staffing constraints. However, efforts to increase consistency in decision-making, such as refining and publishing Operational Guidance, have had mixed impacts. Other efforts, including the creation of Typical Support Packages (see Box 17), have resulted in a more opaque process.

> *"the assessment process is shrouded in a lack of transparency... leaving many Participants and their families in the dark about... what criteria the NDIA uses to determine the level of funding allocated... [This] can lead to frustration for Participants, who would feel that the decisions of the NDIA are unjustified or unfair." – Provider* [613]

Box 17: Introduction to Typical Support Packages

At the beginning of the transition period, the NDIA introduced a new process for determining participants' support packages, using reference package data.

During planning, participants are allocated a Typical Support Package based on their reference group (which is determined by their age, disability type and level of function). These Typical Support Packages were introduced by the NDIA to assist delegates in making reasonable and necessary decisions. This 'resulted in more plans being in line with benchmark costs (compared to the trial period).'[614]

A Typical Support Package is an indicative funding amount that is automatically generated by the guided planning process based on information collected and entered into the NDIA's Customer Relationship Management system. This gives an indication to the planner of an appropriate budget for the participant, based on adjustments to reference packages. [615] There is limited transparency about the reference packages and the Typical Support Packages.

Planners use Typical Support Packages as a benchmark to guide budget setting and help them understand if the plan they are building is within an expected range. Planners have to provide justification if they propose a budget outside of an acceptable range of the Typical Support Package.

The use of Typical Support Packages has caused significant issues including:

- Most participants are unaware that a Typical Support Package is being used to inform budget decisions. The lack of transparency has created significant confusion and distrust.
- Reference packages and Typical Support Packages were built early on in the NDIS (at the start of the transition period) using historical funding levels and expert advice. The underlying data and assumptions hasn't been made available publicly or been tested for validity in a transparent way.
- There is no measure for quality in these benchmarks, which means that it's not clear if participants are not being supported in a way that drives better outcomes.
- The Typical Support Package can provide different benchmarks for the same person if they select a different primary disability. This is particularly concerning for individuals with co-occurring disabilities and means the benchmark may be inaccurate for people with complex needs, multiple disabilities and intersectional experience, and for participants without a formal diagnosis.

Figure 38: Visual on how reference packages and Typical Support Packages fit into the planning process[616]
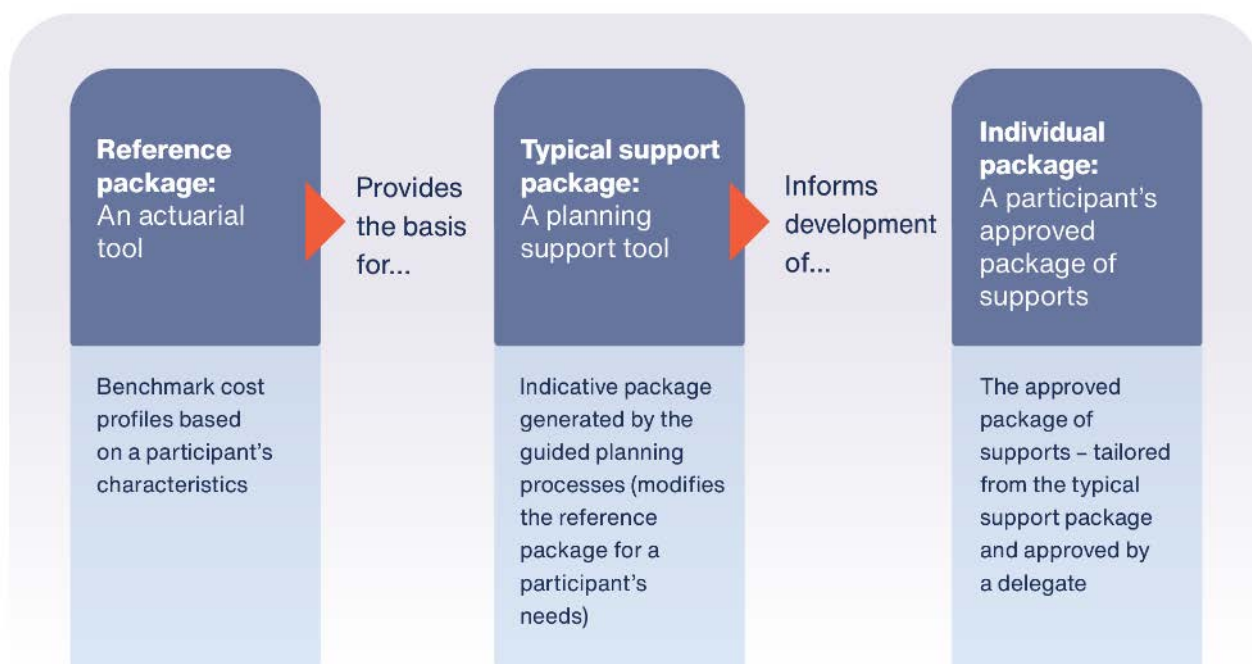
The processes for reviewing decisions

We have also received considerable feedback in relation to the adequacy of internal NDIA review processes and the external AAT review process.

A submission from four members of the Independent Expert Review (IER), a trial independent process established by the NDIA in late 2022 to address the backlog of 5,000 AAT cases, has made

a number of suggestions to address the overall architecture of decision-making and review in the NDIS. This included the need to establish an ongoing independent review process at an intermediate level between an internal NDIS review and the AAT.[617] The submission amplifies much of the feedback from participants and families to the Review, and suggests several systemic issues with the scheme's decision-making framework:

> *"....our observations of the decision-making processes are that:*
> - *Internal reviews tended to defend rather than re-examine previous decisions;*
> - *Attempts at resolution of disputes relied on adversarial legalistic brinkmanship to produce the result;*
> - *In many cases, there appeared to be a failure to follow the evidence in expert reports and lived experience; and*
> - *The Agency often appears to have a primary focus on the costs of supports and trying to reduce them." – Independent Expert Reviewers* [618]

This indicates that an over-reliance on controlling costs sometimes led to inexplicable decisions and suggests that clearer policy and guidance is needed for delegates and internal reviewers on what should be considered reasonable and necessary, appropriate evidence for NDIS purposes and value for money, including better developing what would be a more appropriate baseline of supports.

Implementing plans

We have heard that plans are complex and confusing, and participants are not being sufficiently supported to understand or implement them.

Plan letters are long, difficult to understand, and use vague and complex terminology (see Figure 35). Support categories within plans unnecessarily restrict how funding can be used to meet need, and the rules on how funding can be spent are complex. Many participants are uncertain about how they can use their funding and fearful of breaking the rules. Participants often receive contradictory advice from the NDIA and Partners in the Community. This creates inequities between those who have been in the NDIS longer or learnt to navigate the scheme and those who require more support to understand complex requirements.

Participants do not consistently receive the support they need to understand or implement their plans. While a significant amount of resourcing is consumed managing the planning process described above, there is very little available for a participant to find and use supports once a plan has been approved. Participants are 'handed off' to intermediaries to support plan implementation. But most participants have not been able to access practical support from Partners in the Community and access to and the quality of Support Coordination is inconsistent. Plan Managers are largely focussed on processing invoices, with little and inconsistent help to monitor spending and manage funding.

Choice and control is one of the pillars of the NDIS and was one of the reasons people with disability, their families and supporters campaigned so hard for its introduction. For the principle to

be realised in practice however, participants must have access to accurate and up to date information about supports, have the ability and capacity to make decisions based on that information and feel empowered as consumers to navigate and negotiate. The history of rationed and block funded disability services prior to the NDIS means few participants had the opportunity to develop and exercise choice prior to the scheme's introduction. And there has been limited investment in supporting participants to become the empowered consumers the scheme assumes them to be. When coupled with limits to how NDIS funding can be used, and the lack of support to use it, many participants express frustration that genuine choice and control is yet to become a reality despite the scheme's good intent.

Plans are complex and don't provide enough flexibility to allow needs-based spending

Participants and families told the Review it can be difficult to understand what supports are in their plan and how funding can be used. Despite the length of document, plans include limited guidance to participants on how funding was calculated, what supports were included or how funding can be used. Part of this challenge is that plans and some of the information included in plans are required under the NDIS Act. This has meant that plans have become documents to meet legal requirements, rather than inclusive, useful documents that help participants understand how their funding can help them live a good, inclusive life.

In the absence of good information and support, some participants are so fearful of doing the wrong thing that they choose not to use much of their funding. There is a real fear in the community of being audited, being found to have used funds inappropriately and having to re-pay the NDIA a significant amount of money. This is understandable given often limited financial resources of many participants.

> *"I am increasingly anxious that my funding will be changed to Agency Managed and I'll be made to repay funds. I'm self-managed & spending in-line with my plan and using the self-management checklist but there are lots of bad tales coming through of people switched over tiny things." – Participant* [619]

> *"My wellbeing and health is impacted. The system creates stress as you worry about the future and also making mistakes on how you use your funds in your plan. The guidelines are difficult to understand and navigate." – Participant* [620]

> *"We are self-managed and I want to feel confident that I can make purchases that fit in with our goals. Though I have viewed and read that being self-managed allows us to use the budget as best we can, there often seems to be conflicting information and I don't want to live in fear of being audited and having to repay or have self-managed revoked which is what some people are claiming." – Carer* [621]

Many of the issues with plan complexity stem from the focus on approving individual supports. This focus on individual supports then flows through to the plan and results in funding allocated to

different categories or "buckets". There are then rules for spending in different categories and some individual supports.

Having funding split into so many categories creates avoidable complexity. In the ten years since the scheme was introduced, funding in the core category has gradually become more flexible. Capacity building funding however is not. Funding cannot be used interchangeably between the categories. As a result funding can be underutilised in one category but not able to be moved to another. Participants can have enough total funding for a required support, but they don't have enough funding in the right sub-category or in the case of capacity building the right line item. Even when there may be flexibility, participants don't always understand how this works and often receive conflicting information about how funding can be used from different people.

> *"You're allocated a certain amount of money in your plan, but it's too compartmentalised, it's inflexible. You might use up all the money in one portion, while you still have the money in a different section that can't cross over. You can't use the money for just what needs to be done. It's got to be done within a specific range."*
> *– Voice at the Table [622]*

Rigidly itemised plans disempower and frustrate participants. If an overall budget category is based on potential differences between different participants' needs, it is logical that rules should allow spending to be flexibly tailored to an individual participant's particular support needs. However, this is not currently the case. We heard of instances where participants were prevented from using their funding in innovative and cost-effective ways to meet their needs. Instead, they were required to select more expensive supports simply to comply with budget rules.

> *"I feel like I'm being hampered from using funding in ways I'd like or choose due to strict rules." – Participant and Carer [623]*

> *"More flexibility is required in response to using funding to connect with friends and family, learn new skills and try new things. Funding is prescriptive and cannot be easily changed to suit the person's requirements in relation to their needs." – Provider[624]*

The more specific a plan and its rules governing funding categories, the more often adjustments will be required to the plan to ensure a participant's needs can be met. This means that regular plan reviews are a necessary feature of the current approach. Allowing participants to spend more flexibly within their overall budget allocation would assist participants to meet their changing needs without requiring them to apply for a change of circumstances and a new budget.

Many, if not most, participants are fearful of plan reviews. This is because plan reviews have been characterised by poor communication around the timing of reviews and what they entail, and failure to give adequate explanations for decisions. As a result, participants are often choosing to roll-over plans that should be checked more regularly to ensure they still reflect the participant's

need. The combination of inflexible plans and fear and mistrust about plan reviews is making it hard for participants to get the support they need.

> *"Mine are now every two or three years and I appreciate that. I still don't enjoy having to tell a stranger how my disease has progressed, and I try not to rock the boat to ensure that my funding doesn't cut like so many were during the last government." – Survey Respondent* [625]

> *"I am too terrified to have to face a plan review and have to justify my needs when I see what has happened to other people... [I] can't leave my house as no one can transport my electric wheelchair and I am too scared to... request a vehicle modification as scared about having a plan review and having my current funding cut." – Participant* [626]

> *"The evidence is not being really considered. I live in constant fear that I will not be given adequate support to be independent and each [time] there is a new plan that's what happens" – Survey Respondent* [627]

A culture of distrust and lack of certainty about future funding also impacts on how participants use their funding. We have heard that participants are fearful that if they don't use their funding it will mean it is reduced in the future. Similarly, participants are also worried that if they tell the NDIA that a service has been effective in improving their capacity, they may have it removed or reduced in future plans.

> *"There is a pervasive theme of distrust and fear that shape how participants experience and relate to the NDIS. Experiences with the NDIA, service providers and broader public narratives about the NDIA has resulted in fear of losing supports, fear of not being believed, fear of coercion, fear of experiencing discrimination, fear of abuse and neglect, fear of co-opting of concepts such as recovery." – Advocate* [628]

> *"[I have a] fear of losing funding due to fluctuating condition and due to having times where I may not use as much funding." – Participant* [629]

> *"If participants report their supports are improving their lives; for some, there is the immediate fear that future supports will be reduced automatically because they are perceived as not being needed as much." – Participant* [630]

> *"I think the NDIS has a problem with punishing improvement. As soon as any improvement is made, funding is cut. It actually incentivises not making progress, whereas the ultimate goal is encourage improvement. Keeping funding available and not suddenly whipping it away will ultimately save the government money, especially when it comes to allied health services. No one really wants to see a speech therapist more than they need to... At the moment, the system is set up that if you don't' use it*

(funding for therapy), you lose it (next plan). I fear I may lose my funding for speech therapy because I haven't used all of it." – Participant [631]

Participants do not receive consistent, effective support to spend their budgets on supports they need

Funding in a participant's plan can be managed in several ways and is mostly considered in terms of the rules that apply to how a participant may manage their funds:

> Agency managed: Agency managed participants must use registered providers and adhere to the prices limits set by the NDIA.
> Plan managed by a registered provider: Plan managed participants must use a registered plan manager but may then use registered or unregistered providers (with some exceptions), who cannot be paid above the upper price limit set by the NDIA.
> Self-managed by the participant or a nominee: Self-managed have the greatest level of flexibility. They may engage registered or unregistered providers (with some exceptions) and may negotiate a payment rate lower or higher than the price limits set by the NDIA.

This creates a situation in which participants can choose their preferred level of control (subject to a decision by the NDIA on their decision-making capacity). In making their choice, participants (and any nominees) must weigh up the benefits of greater flexibility that comes with self-managing against administrative and other considerations. The decision isn't always easy and varies depending on individual circumstances – we have seen many who self-manage report challenges (Figure 39).

Plan managers are meant to support participants to self-direct and manage their funding.[632] However, in practice this support is very limited and inconsistent with most plan managers primarily focused on administrative tasks – such as processing invoices, maintaining financial reporting and budget tracking, and financial administration. Participants have inconsistent help to monitor spending and manage funding, with some plan managers acting as 'gatekeepers' while other plan managers doing little to monitor spending. Very few participants have funding for their plan manager to support capacity building for self-management.

> *"The last plan manager changed my plan from self-managed to agency managed and didn't event tell me about it. I only found out when my support workers complained about not being paid" – Focus Group Attendee [633]*

Figure 39: Summary of 2022 NDIS Participant Survey on Self-Management Survey asked approximately 800 self-managed participants or nominees, 'What are the biggest challenges of self-managing?'[634]
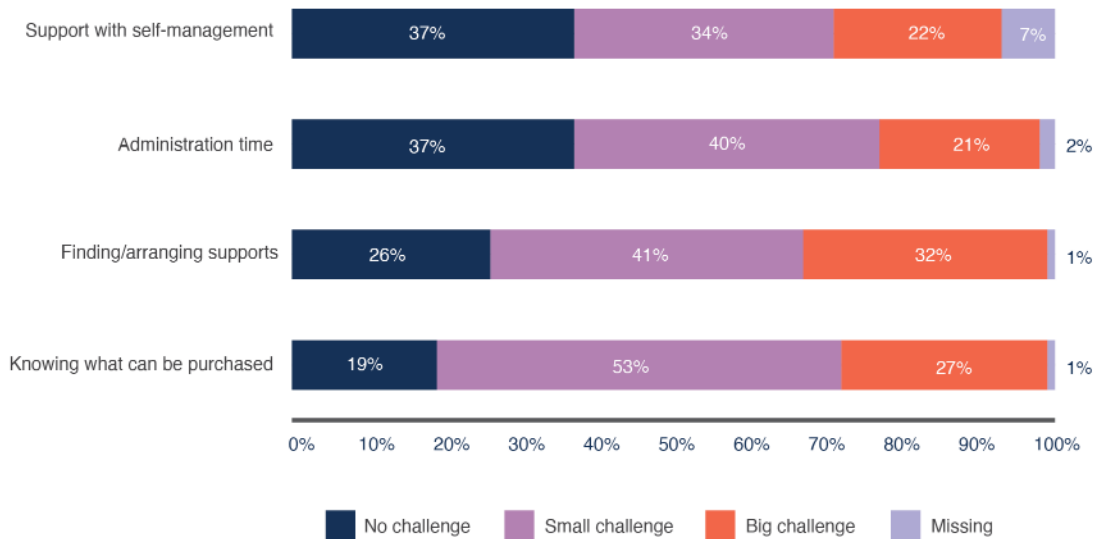
In addition to financial management support, there is supposed to be general coordination support available for participants, their Plan Nominees and families. This was originally provided by the NDIS during the trial and then transferred to Partners in the Community. However, as with previous reviews and inquiries, we have consistently heard that this support isn't practically available. Funding and staffing constraints in the NDIA have meant Partners in the Community have been diverted from their intended role to carry out access and planning activities.

The gap for participants was intended to be filled by support coordination. This support is currently funded for approximately 276,000 participants (45 per cent of all participants). The majority of support coordination is provided for participants over the age of 18. Almost 210,000 of the total 276,000 participants with funding for support coordination are over the age of 18 (70 per cent of participants over the age of 18).[635] As this suggests, access to this funded support is not consistently available and the quality of support coordination is highly variable. In Section 3.1.6 we explore the issue of how participants can be better supported to navigate supports and implement their funding in more detail.

For participants entering under section 25 of the NDIS Act, there is also no approach for the NDIA to monitor whether a plan is achieving the aims of early intervention, or to support a participant to adjust their supports or provider if they are not helping a person achieve the outcomes that are important to them.

There is very little data being collected to better understand the impact of particular supports or approaches on a participant's quality of life, outcomes or level of support needs over time. Without monitoring and evaluating an individual's progress over time, there is no way of determining

whether the NDIS is working as well as it could be. This is important for all participants and government.

2.2.2. Budgets should be set at a whole-of-person level and implemented through a trust-based and flexible approach

We are proposing a package of reforms to the NDIS participant pathway. Increasing the scheme's investment in getting the overall budget right for participants and giving participants more flexibility, trust and support to use that budget are critically important to improving the experience and outcomes for participants and ensuring scheme sustainability in the long term.

The future approach should be consistently needs-based – from how budgets are determined through to how those budgets are implemented. Budgets should reflect each participant's disability-related support needs based on a holistic picture of each person's circumstances and life stage. This is in contrast to the current focus on primary diagnosis.

Budgets should be more flexible to allow participants to use them based on their individual needs. The increased choice and control that greater flexibility enables should also be underpinned by more and better support being consistently available to participants from locally connected, non-government Navigators. The role of Navigators would be to assist participants to get the most from their budget, build and maintain supports, make connections and move towards better outcomes (see Section 3.1.6).

We propose five main areas for change, improvement and better outcomes for participants and the scheme:

Figure 40: Overview of the proposed changes to budget setting and implementation

How budgets are set and reviewed	**1. Budgets are set at a whole-of-person level**	• This requires reasonable and necessary to be re-defined in the NDIS Act and Rules as the total funding determined to meet the support needs of a participant. • This budget should be based on supports needs and intensity, rather than deficits and impairment.
	2. Needs assessments are used to set whole-of-person budgets	• This requires reliable, structured, and valid assessments to enable NDIA Needs Assessors to identify support needs and intensity. • The NDIA Needs Assessor should identify support types, frequency, and any one-off or time limited supports, creating a whole-of-person budget. • The NDIA Needs Assessor should be a highly skilled, trained and experienced decision-maker.
How participants are allowed and supported to implement their budgets	**3. Greater flexibility in how the budget can be used**	• This requires changes to the budget categories and rules to allow more flexibility in how participants spend their budget. • The flexible budget should combine what was the Core and Capacity Building support budgets into one budget. • There should be minimal exceptions to this flexibility, including a housing and living budget and some stated supports (if relevant).
	4. A local navigation function to support participants	• This requires the creation of a Navigator function to support participants to make a plan to use their budget and to implement that plan. • This support should be available all participants. • Existing similar roles that are working well could be moved into these new roles.
	5. A more trust-based approach to the NDIA overseeing budget use	• This requires a more trust-based approach to how participants can and are supported to use their flexible budget. It should make it easy for participants to comply with rules. • Compliance should be encouraged through guidance and support, with more hands-on involvement only ever used where there are very significant risks or issues.

Overview of the new approach

We recommend the NDIA set more flexible budgets for participants at a whole-of-person level. Whole-of-person means taking a holistic, person-centred approach to understanding and meeting the disability-related support needs of each participant.

This is a significant shift from the current approach in which overall plan budgets are assembled from planner decisions about which individual supports have been approved or declined, often in the absence of any direct relationship with the participant. This should reduce the chance of participants not receiving needed supports because they did not know to ask or could not provide evidence to support their request. This better outcome will arise because the whole-of-person budget will be based on a transparent, understood, structured and equitable process that gathers information about the participant from the participant and others familiar with their circumstances and their support needs.

The first stage in the information gathering process should be a support needs assessment. This would be completed by a skilled and qualified NDIA Needs Assessor with disability expertise who is a trained allied health practitioner, social worker, youth worker or similar. They would need to have disability training and experience, as well as extensive training to complete a needs assessment. This would be a thorough assessment conducted by the person responsible for making the whole-of-person budget decision. This means most participants should be able to meet the decision-maker.

The whole-of-person budget should be more flexible with fewer support categories. It would consist of:

- A flexible budget
- A housing and living budget (if relevant)
- Any stated supports for assistive technology, equipment or other one-off capital costs (if relevant).

Participants should be supported by their Navigator to decide how best to use their budget and develop a plan of action in line with the objects of the NDIS. How this would work is outlined in detail in the next section (see Section 3.1.6).

There should be a manifest commitment based on trust to how the NDIA oversees budget use. Participants should be supported by Navigators to use their budget, to understand and make decisions about their own support needs and priorities within transparent and known rules. There should be a graduated and well-codified approach to responding to significant risks or issues.

Each of these approaches should be implemented gradually using an iterative, inclusive approach to design and testing to ensure all current participants experience a smooth and fair transition to the new arrangements (see Action 3.8).

Figure 41: Outline of the new process
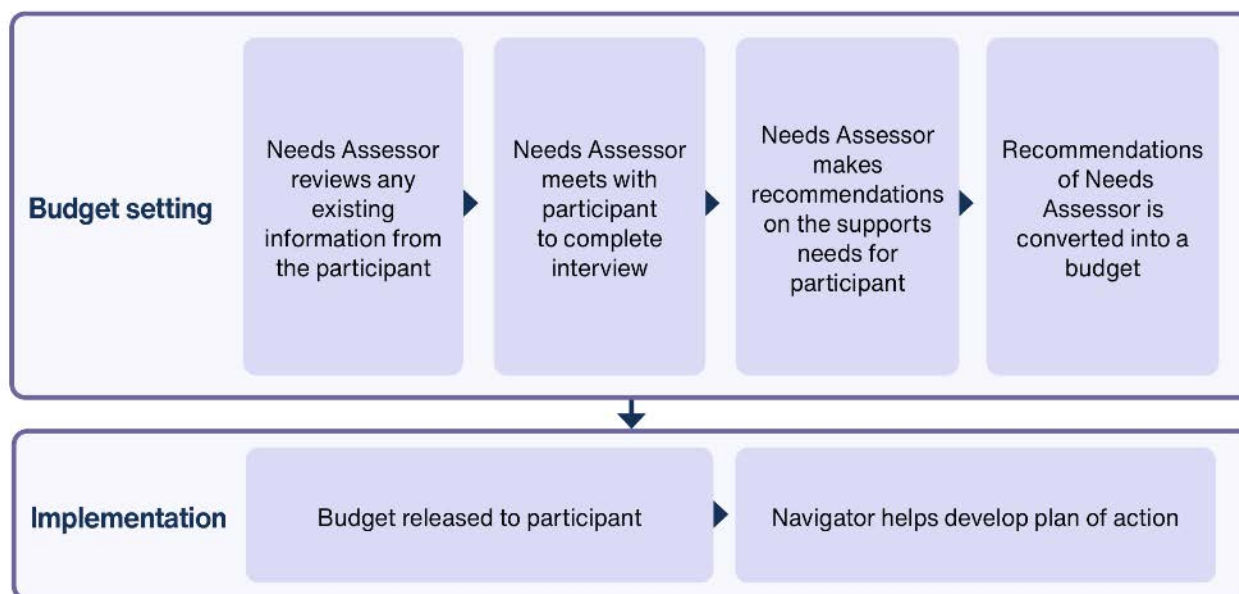
Community guidance on developing the path to needs-based NDIS assessments

The way that the assessment framework and assessments are designed, tested and refined will be crucial for their success. We explored the idea of a holistic needs assessment through a participatory engagement process to develop an initial understanding of key success factors for developing the assessment. This activity was in addition to the extensive engagement undertaken by the Review with people with disability, their families, representative organisations, providers and the disability sector more generally.

The participatory engagement process involved multiple working sessions with people with disability, representative organisations, people with operational and service delivery expertise, and sector representatives. The process was conducted over five months and included 26 working sessions, including:

- 12 sessions with people with lived experience (26 people)
- 8 sessions with a Co-Group (12 people who were a combination of Senior Policy Officers and CEOs from National Representative Organisations and members with lived experience)
- 3 sessions with NDIS providers (9 people)
- 3 sessions with NDIA staff and NDIS intermediaries (10 people).

The sessions focused on key ideas for the Review, including information gathering for budget setting, and navigation. The engagement process involved the Review testing assumptions about these ideas and refining our thinking based on feedback. Although this process involved only a small sample of the diverse disability community, the repeat sessions with the same groups enhanced insights from our broader engagement through further discussion and testing.

Building on feedback from this participatory engagement process, and conversations with assessment experts, we have formulated initial considerations to guide the NDIS Experience Design Office in its design activity of the needs assessment process after the Review (see Box 18).

The Co-Group independently developed its set of principles and considerations that relate to the development and implementation of NDIS needs assessment. They are distinct from the considerations below. The *Co-Group Feedback to the NDIS Review Panel* is provided at Appendix B.

Box 18: Considerations for needs assessment design

The NDIS Experience Design Office should follow the approach set out in Action 3.8 to design the needs assessment. This should be based on the considerations below, alongside the Co-Group *Feedback to the NDIS Review Panel* (Appendix B).

The NDIS Experience Design Office will need to report on progress to the NDIS Review Implementation Advisory Committee (see Action 24.1), which will also include disability sector representatives and people with disability, families and carers.

The success of these reforms requires that the disability community can hold the NDIA, including the NDIS Experience Design Office, accountable for this process.

Legitimate and trusted:

- The assessment must be transparently designed with participants and people with disability expertise (see Actions 3.4 and 3.8), through the recommended implementation architecture (see Action 24.1).
- The assessment process must ultimately be acceptable to participants, families and nominees. Characteristics of an assessment that may be acceptable include; being transparent, thorough and valid without being invasive or overly burdensome. Without legitimacy and trust of the disability community, the assessment will not be able to be successfully implemented.
- The assessment process must also recognise diversity of needs across the community. This means that the process needs to meaningfully consider how core identity characteristics such as gender, sexuality, age, cultural and religious beliefs intersect to impact needs. This lens needs to be applied over a broad range of domains and tested with intersectional community leaders to be effective.
- For First Nations people, a culturally informed and gender sensitive approach should be taken. A tailored First Nations approach must be informed by a social and emotional wellbeing framework and prioritise cultural determinants of health (connection to Country, family, kinship and community, Indigenous beliefs and knowledge, cultural expression and continuity, Indigenous languages and self-determination and leadership).[636] To be successful, this process must be designed in partnership with First Nations people with disability.

"Aboriginal and Torres Strait Islander peoples' approach to health and wellbeing is holistic, placing equal emphasis on physical, social, emotional and cultural wellbeing, which are interconnected. Disability also needs to be understood through this holistic lens, which centres culture, community and Country." – Lowitja Institute[637]

Valid, reliable and consistent:

The assessment must:

- Be able to consistently measure support needs and intensity. It should be mapped to the International Classification of Functioning, Disability and Health.
- Be valid across different groups of participants, including the full range of age groups and disability types (including multiple disabilities).
- Deliver a valid assessment of need without imposing excessive time or cost requirements on participants or the NDIS.

Person-centred and strength-based:

The assessment process must capture a comprehensive and holistic picture of the participant's needs, including circumstance and life stage. This means the process should have the following characteristics:

- *Holistic:* A participant's environment, informal supports, and outcomes they value must be captured. Significant life transitions such as moving out of home and transition to employment should be considered as part of the assessment and budget setting. Carer and family impact statements should form part of the needs assessment.
- *Flexible:* Interviews should be able to be semi-structured so that the process can allow assessors to respond to the individual and establish trust in a way that does not impact reliability.
- *Trusting:* There must be an opportunity for participants and nominees to self-report their needs, circumstances and life stage, and provide existing information from trusted professionals. This may include personal statements, videos, or written information.
- *Efficient:* The process must allow for data transfer from the access request and previous interactions with the NDIA, including assessment processes, as well as data from other service systems (where consent is provided). Participants should not have to restate information.
- *Transparent:* There must be full transparency of assessment questions, outputs and how different evidence has been weighed. Participants and nominees must have a clear understanding of how needs have been assessed. Assessment questions and research on validity should be publicly available.

Proportionate and responsive:

- The assessment must be responsive and proportional to the need of the individual.

- A person with relatively lower needs and expected to have a lower budget should not be required to undergo the same intensity or length of assessment as a person with relatively higher needs and expected to have a larger budget. This means the approach should reflect the individual.
- The assessment must dynamically respond to information to be able to deliver this functionality.

How budgets are set and reviewed

Setting budgets at a whole-of-person level

This would be implemented through the introduction of a holistic needs assessment and changes to section 34 of the NDIS Act (as well as the NDIS Rules), which currently requires each support item to be determined to be reasonable and necessary.

> **Box 19: NDIS Act (section 34) – Reasonable and necessary supports** (emphasis added)
>
> "For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of *each such support*."

The proposed approach means that a skilled NDIA Needs Assessor would make a recommendation on the support needs for the participant, based on the range of information described previously. A transparent calculation would then be used to develop a reasonable and necessary whole-of-person budget based on the recommendation of the NDIA Needs Assessor.

The benefit of this approach is that it enables the overall budget decision to consider each participant as a whole person with expertise and understanding of their own support needs. The process would engender a deeper understanding of each participant's support needs, based on the overall impact of their disability (disabilities), level of impairment, life stage and circumstances.

This means a participant would not be required to collect costly evidence to justify every individual support item because the NDIA Needs Assessor would have worked with the participant to review any information they already possess to confirm support-related needs. It would also end the conflict over primary and secondary diagnoses as a support needs assessment will capture the impact of all conditions on a person's daily life.

Using needs assessments to set whole-of-person budgets

We recommend a more structured way to gather information with, from and about participants, their circumstances and support needs to inform the whole-of-person budget. This needs-based assessment process would be comprised of three key components:

A customised NDIS assessment process to structure and ensure complete information gathering.

Before being introduced this new assessment must be designed, tested and evaluated in partnership with the disability community to be both effective and acceptable.

A skilled NDIA Needs Assessor who is responsible for completing the needs assessment and making a recommendation about a participants support needs and support intensity.

The method to use the needs assessment to determine a reasonable and necessary budget.

<u>A customised NDIS needs assessment process</u>

Under the new approach, the NDIA would use a comprehensive assessment to consider a participant's support needs, including their circumstances (such as existing and informal supports), as well as their life stage and environment. We heard that the NDIS needs a transparent, valid assessment process to improve the quality of funding decisions.

> *"The utilisation of a simple well-tested bespoke NDIS assessment tool should assist in calibrating the decisions of NDIA staff and ensure each participant's NDIS budget is fair and equitable when compared to those of more than half a million other Participants. This should mean that the draft budget signal produced by the assessment is both reasonable for the participant's needs, and equitable in relation to other participants. Notably, other jurisdictions have previously applied this type of approach, such as local authorities in the United Kingdom through their Resource Allocation System (RAS) for individualised funding, and appear to have had far fewer issues compared to the current NDIS arrangements." – JFA Purple Orange* [638]

> *"Complex decisions such as what is appropriate funding for people with diverse disability-related needs requires a sophisticated process of assessment and a system conductive to good decision-making. Ideally, this should combine processes that derive a comprehensive understanding of complex needs and individual contexts with valid assessment mechanisms and clear values to generate transparent decisions." – Griffith University* [639]

> *"Dramatically reduce complexity, need for ongoing reassessment, reports, overwhelming burden of administrative hurdles, complex language, evidence, repeated degrading questions about what is wrong with us, more trauma informed and sensitive support to engage, less adversarial and inconsistency." – Survey Respondent* [640]

> *"It is a struggle every time. I would love to be able to go into a planning process feeling confident that people would really listen... allow me time to check that my needs had been understood and presented well so that the planner could code it accurately to get the funding I need"... [the planning process should be] "...ideally face to face meetings that involve being around the individual... families and their loved ones need support not red tape." – Survey Respondent* [641]

Measuring need requires a structured approach to identify the specific volume and type of support needed to enable a person to participate in valued settings and activities. This is where a needs assessment comes in.

A needs assessment provides this structure by establishing the domains (broader categories) and activities (specific areas to investigate) that an assessor uses. An assessment of need is undertaken for each activity, typically by identifying the type, frequency and volume of supports required. These can be added together to provide an assessment of need for each domain and all activities can be added together to provide an assessment of need for the whole person. This can create either:

- Total number of support hours across different supports. Support hours can then be multiplied by the expected cost to deliver each hour to arrive at a total amount of funding. The cost of other capital items is added on-top.
- Score that represents the level of need. A needs score can be linked to an amount or level of funding based on what is typically required to meet the needs of a person with the same or very similar score in the same circumstance. The cost of other capital items is added on-top.

A focus on support needs is intrinsically a more person-centred and strengths-based approach than the functional assessments and deficit-based approach used currently (see Box 20).

Box 20: Simple comparison of functional assessments and needs assessments[642]

A functional assessment may say: "Tamryn cannot count change" or "Tamryn's financial literacy is at the 2nd percentile, compared to her peers".

A needs assessment focuses on what support someone needs to achieve the kind of life they value, and so may say something like "Tamryn needs support to use her bank card when shopping" or "Tamyn needs support to remember to top up the funds for her bus pass".

This process must include consistent questions and measures of support needs across a range of domains mapped to the International Classification of Functioning, Disability and Health. A set of questions are required that can be tailored in delivery based on the participant and the information already provided by the participant and their trusted treating professionals to the Needs Assessor. The assessment questions can be asked in a semi-structured way, to enable the Needs Assessor to take an approach that works for the particular person being assessed.

For example, for a participant who has given a clear indication of their needs in some domains in information sent before the interview, more time may be spent on activities and domains that may be less clear for the assessor. This may mean that assessment interviews are shorter or focussed on different areas for some participants. However, to ensure validity and consistency, the full assessment will be completed, and all answers validated with the participant, regardless of the nature of their diagnosis or impairment. The ability to tailor an assessment so that it works for

participants with the diversity of needs while also being consistently completed relies on an expert workforce. This is discussed in further detail in the following section.

A valid and reliable NDIS needs assessment will need to be developed to generate a holistic picture of support needs. There are several existing supports needs assessments used internationally and in Australia. Short case studies of each of these assessments are provided in Figure 42 and how they are used to set budgets in Box 23.

The Review has intentionally not attempted to select or recommend any one (or more) particular assessment. A scheme as large, diverse and world leading as the NDIS requires a needs assessment that has been specifically designed for the purpose and groups it serves.

This also has the strong benefit of ensuring the disability community are fully engaged partners in the design, testing and evaluation of potential assessment models and how assessment can and should work. Community involvement in the development process is essential to achieving the fair, equitable and empowering assessment framework that participants need. This is a critical lesson from the attempted introduction of Independent Assessments in 2021.

The new assessment framework and process must be fit for the purposes for which they will be used – genuinely improving the participant experience and resulting in more transparent and consistent outcomes. The process of designing, testing and refining needs assessments must be inclusive and highly transparent. Any process that is not inclusive will fail if the system does not investment in its legitimacy.

The design of new assessment processes should involve testing of existing relevant needs assessments with the groups they have been validated for, as well as trialling the process. The aim should be to test their application and learn from this experience. This should not be linked to funding decisions until testing and trialling is complete. The testing should enable participants and families to begin to experience what a needs assessment may entail. It should also allow improvements from experiences in other contexts. This testing may reveal that existing assessments can be made fit-for-purpose with customisation designed through a transparent process with the disability community.

Testing will, at some point, lead to pilots and trials involving consenting participants. These development phases rely upon the commitment and engagement of people with disability, their representative organisations and credible, respected advisers. These arrangements should form part of the five-year transition and implementation process.

The significant work required to design, test and refine a needs assessment will not be starting from scratch. The Review's participatory engagement process (described in the previous section) provides an excellent foundation for the design work to follow (Appendix B).

In addition, short case studies for existing needs-based assessments are provided in Figure 42 and in Box 23. These present a good starting point for the design process, to begin testing their suitability for the groups for whom they have been validated. There should be a more

comprehensive exercise to identify potential assessments that the disability community wants to include as part of the testing process.

Case studies have been included for:

- Camberwell Assessment of Need (CAN) and Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities (CANDID).
- Care and Need Scale (CANS). This is currently accepted by the NDIA for those with acquired brain injury.
- Instrument for the Classification and Assessment of Support Needs (I-CAN).
- Supports Intensity Scale Adult version (SIS-A).

Additional case studies for the Paediatric Care and Needs Scale (PCANS) and Supports Intensity Scale Children's version (SIS-C) are provided in Section 5.4.3.

Figure 42: Examples of case studies for existing needs-based assessments

Camberwell Assessment of Need (CAN)[643]
Link to more information
Overview & current use • CAN is a family of questionnaires can be used to assess the wide range of problems which can be experienced by people who have mental health problems. • It assesses the health and social needs of adults. • There are four versions of the adult CAN (CANSAS, CANSAS-P, CAN-R and CAN-C) for use in clinical work and in research studies. The CAN-R is the most detailed assessment.

Domains and scoring	How the assessment process works
Domains: CAN assesses the health and social needs of adults across 22 domains of life: • Psychotic symptoms, psychological distress, company, daytime activities, looking after the home, physical health, money, intimate relationships, food, transport, accommodation, sexual expression, information on condition and treatment, self-care, safety to self, alcohol, childcare, basic education, social benefits, safety to others, telephone and drugs. **Scoring:** The scoring approach is based on the total number of unmet needs, total number of met needs and the total number of needs across the domains. This produces a needs score.	**Process:** An assessor conducts a semi structured interview with the individual and/or their representatives using the domains as a checklist of areas to cover during a face-to-face interview. There is a staff assessment and a service user assessment. **Assessor Skills and Training:** Training is available for the CAN-R, which is the most comprehensive version of the CAN assessment. However, the tool has been designed for use by all health care professionals and does not require additional formal training. **Assessment Model:** The assessment model focuses on understanding the unique challenges faced by individuals and planning appropriate care and support to help them to lead an independent life.

Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID)[644]

Link to more information

Overview & current use

- CANDID is a variation of the Camberwell Assessment of Need (see case study above) to enable it to be used with persons with an intellectual disability.
- A validity and reliability study conducted in 2000 concluded that the assessment tool is a brief and reliable instrument for assessing the needs of people in this group.

Domains and scoring	How the assessment process works
Domains: The CANDID assesses met and unmet needs in 25 domains: • Accommodation, food, looking after the home, self-care, daytime activities, general physical health, eyesight and hearing, mobility, seizures, major mental health problems, minor mental health problems, information, safety to self, exploitation risk, safety to others, inappropriate behaviour, substance misuse, communication, social relationships, sexual expression, caring for someone else, basic education, transport, money and budgeting, welfare benefits. **Scoring:** The scoring approach is based on the total number of unmet needs, total number of met needs and the total number of needs across the domains. This produces a needs score.	**Process:** An assessor conducts a semi-structured interview to assess an individual's needs. The assessor uses prompting questions to guide the discussion with the goal of establishing whether an individual has a need (met or unmet in the last 4 weeks) in each of the 25 assessment domains. The length of assessment depends on whether the short form (CANDID-S) or longer form (CANDID-R) is used. **Assessor Skills and Training:** Same as above for CAN, training is available for the CANDID-R / CAN-R, the most comprehensive variation of CAN. However, the tool has been designed for use by all health care professionals and does not require additional formal training. **Assessment Model:** The assessment model focuses on how much help is needed, the type and satisfaction with support provided by local services to help people live independent lives.

Care and need scale (CANS)[645]

Link to more information

Overview & current use
- The CANS was developed to measure the support needs experienced by older adolescents and adults with a traumatic brain injury. There is a paediatric variation (P-CANS) available for the ages of 5 to 15 years (see Section 5.4.3).
- CANS is currently accepted by the NDIA for those with acquired brain injury. It is also used in Australia for workers compensation schemes.
- CANS was compared with three other assessment tools to test its validity in 2004. A sample study of 67 people, who sustained severe traumatic brain injury 20-26 years previously, indicated that further testing in the long term would be beneficial.

Domains and scoring	How the assessment process works
Domains: The CANS comprises two sections: a Needs Checklist and Support Levels. It groups health and social domains of life into groups to assess the type and level of support required. - **GROUP A**: Requires nursing care and/or support or monitoring of severe behavioural/cognitive disabilities and/or assistance with very basic activities of daily living. - **GROUP B:** Requires assistance, supervision, direction and/or cueing for basic activities of daily living. - **GROUP C**: Requires assistance, supervision, direction and/or cueing for instrumental ADLs and/or social participation. - **GROUP D**: Requires supports. - **GROUP E:** Does not require supports. **Scoring:** The type of support is determined through the needs checklist and the extent, intensity and frequency of support is determined through the support levels section.	**Process:** The CANS comprises two sections: a Needs Checklist and Support Levels. The assessment is conducted by an assessor who has detailed current knowledge of the individual. Nominees or a support person known to the individual or the person with the brain injury directly can also contribute to the assessment. Assessors can also complete an assessment on the basis of information derived from the patient's medical record. The assessment may take up to an hour to complete. **Assessor Skills and Training:** Same as above for CAN. **Assessment Model:** The assessment model focuses on a number of factors, including (but not restricted to): - the severity of an individual's limitation - the combined effects of all the limitations - the influence of other impairments such as memory - contextual factors, such as the availability of environmental supports (equipment, aids, services, social supports).

Instrument for the Classification and Assessment of Support Needs (I-CAN)[646]

Link to more information

Overview & current use

- Developed and administered by the Australian Centre for Disability Studies in 2002.
- A detailed needs-based assessment tool for adults with disability, including psychosocial disability. It is not currently validated for children.
- It is currently used by the Department of Health for the Disability Support for Older Australians Program.
- Over 5,000 people have been assessed using a version of this tool, mainly in supported accommodation.

Domains and scoring	How the assessment process works
Domains: Based on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF). The ICFs Activity and Participation domains are supplemented by three domains based on health and wellbeing: 1. Mobility 2. Domestic Life 3. Self-Care 4. Community, Social & Civic Life 5. Communication 6. Learning & Applying Knowledge 7. General Tasks and Demands 8. Lifelong Learning 9. Interpersonal Interactions & Relationships 10. Behaviours of Concern 11. Mental & Emotional Health 12. Physical Health Each domain is then broken into specific activities which are scored to determine the level of support needs. **Scoring:** Scoring for the I-CAN is broken down into two components of support (frequency and type) with each rated on a Likert scale. I-CAN also allows for significant amount of qualitative information to be included in the assessment report.	**Process:** Can take 5-10 hours to perform (note that this includes preparation time in addition to interview time). Involves a semi-structured interview and order of completion does not impact the results. **Assessor Skills & Training:** Only those certified can conduct an I-CAN. Verification requires 1-day formal training and to complete an assessment with a client to an approved standard. Assessors generally have experience in clinical assessment. Certification must be renewed annually. Assessors require a license to use the I-CAN assessment tool. **Assessment Model:** The I-CAN is based on a model in which supports are considered: - An integral part of all human functioning, - Dependent on a person's health, life pursuits and environments, and not an enduring characteristic of the person, - Needed according to a person's environment and chosen valued life pursuits.

Supports Intensity Scale Adult version (SIS-A)[647]

Link to more information

Overview & current use

- Developed and is administered by the American Association on Intellectual and Developmental Disabilities (AAIDD).
- A detailed needs-based assessment tool designed for people aged 16 years and older with intellectual and developmental disabilities. A version is available for children (see Section 5.4.3).
- The SIS-A was normed on a population of over 1,300 people with intellectual and developmental disabilities in the US and Canada.

Domains and scoring	How the assessment process works
Domains: The SIS-A measures an individual's exceptional medical and behavioural support needs and support needs for life activities in the areas of: 1. Home living 2. Community living 3. Lifelong learning 4. Employment 5. Health and safety 6. Social activities 7. Protection and advocacy Each area has more detail activities which are scored to determine the level of support needs. **Scoring:** The assessor ranks each activity using a Likert scale according to frequency, amount, and type of support needed. This provides a support intensity score for each area and a total score.	**Process:** Can take 2-2.5 hours to conduct the interview only. Involves a semi-structured interview and order of completion does not impact the results. **Assessor Skills and Training:** Assessors should be trained in the SIS-A to administer it. AAIDD recommends that the SIS is administered by a professional who has completed a 4-year degree program and is working in the field of human services. Others who have experience conducting individual assessments and possess an extensive knowledge of behaviour rating or psychological testing principles can also administer the assessment. **Assessment Model:** The SIS suite of tools shift the focus from deficiencies to support needs, by evaluating the practical supports a person needs to lead an independent life. It also captures the needs and goals a person wants to prioritise, as well as medical and behavioural information.

<u>A skilled NDIA Needs Assessor</u>

A key element of the proposed needs assessment approach is a skilled workforce of NDIA Needs Assessors. This will be very different to the current NDIA delegate workforce. Needs Assessors will be responsible for completing the needs assessment and determining the reasonable and necessary whole-of-person budget. We have consistently heard there is a need for highly skilled and reliable decision-makers. We have also heard it is essential they have met the participant.

Allied health professionals, social workers and youth workers with disability training and experience, are likely to have the most suitable backgrounds to be conducting assessments and making decisions based on need. However, formal qualifications may not be available in all circumstances, given other important requirements such as culturally appropriate backgrounds and lived experience of disability.

Needs Assessors must also be appropriately skilled and trained in the assessment process and disability. This expertise is required to engage respectfully and directly with participants and their families, as well as providing accurate and reliable assessments. Box 21 provides more detail on the minimum recommended skills and capabilities of Needs Assessors.

Box 21: Expectations for NDIA Needs Assessors

Assessors must have the skills and experience to conduct assessments in a culturally appropriate and trauma-informed way that is grounded in human rights. They must be able to reliably capture individual support needs, life stage and transition points to inform a whole-of-person budget.

People with lived experience of disability and other disability-related lived experience should be prioritised in recruitment, and proactively sought out and supported into Needs Assessor roles by the NDIA.

In addition, we believe the following qualifications, skills and training are necessary to successfully fulfil the role of a NDIA Needs Assessor:

<u>Qualifications</u>

- We have heard that minimum qualifications in allied health, social work or youth work provide a sound basis for Needs Assessors who can accurately assess the impact of disability on a person's life.
- Careful consideration must be given to any exemptions to these minimum qualification requirements to ensure other factors such as managing complex needs, trauma-informed care and health and safety requirements continue to be met. Where exemptions are applied, additional consideration should be given to how high quality, valid and reliable assessment standards will be maintained.

<u>Skills</u>

- Assessors need culturally appropriate, strengths based and trauma informed interviewing skills. They must be able to work with participants, families and their trusted professionals to understand support needs in a way that focusses on strengths and does not exacerbate trauma - acknowledging that most participants have experienced trauma in their lives.
- For First Nations people, delivery of a trauma-informed practice includes an understanding of the ongoing impacts of colonisation and how that impacts First Nations conceptualisation and language use regarding disability.
- Assessors will receive information from a range of sources and must be able to analyse the evidence provided and understand where an applicant's needs may be higher or lower than the reports or information provided.
- For many First Nations people, it is appropriate that interviewing and information gathering is done by a trusted member of community wherever possible (First Nations or otherwise). Workforce planning and assessment approaches must take this into consideration.

<u>Training</u>

- Assessors must be trained in how to conduct the assessment to an appropriate level of interrater reliability. Interrater reliability means that two independent assessors using the same processes would make very similar or the same assessment of needs. This will require initial and ongoing training and evaluation to ensure assessments are being administered appropriately.
- Assessors will be required to undertake specific disability awareness training to maintain awareness of potential needs that should be considered for people with disability. Assessors will also be required to undertake training in best practice approaches to supported decision-making. This will ensure assessors are able to identify real and potential risks to participant safety and the pattern and intensity of supports needed.
- It is important that the assessors have undertaken training on how need may differ across different cultures. They also require clear guidelines on how this should be recognised with the needs assessment (such as; different approaches to how informal supports are provided, or understanding the support needs associated with cultural obligations such as return to Country).
- All assessors must be trained to deliver culturally safe and gender sensitive approaches through bespoke training designed and delivered by the relevant representative organisations such as First People Disability Network, the National Ethnic Disability Alliance and Women with Disability Australia or other representative organisations.
- While all assessors should be prepared and able to delivery culturally safe and gender responsive services, participants should be able to request (and ideally reserve the right to choose) a First Nations, woman or culturally or linguistically diverse identifying Needs Assessors.

Beyond specific qualifications, skills and training, we have also heard it is crucial that decision-makers are known to participants throughout the assessment process in order to accurately inform the assessment and decisions that will profoundly affect the participant's quality of life. This means the Needs Assessor must have the delegated authority to make the reasonable and necessary whole-of-person budget decisions. This would ensure the majority of participants, supporters and families meet with the person making the critical funding decision.

For a small number of participants with high-value budgets, we anticipate a more senior Needs Assessor with higher delegation authority will be required. For an even smaller number of participants with very high budgets, an NDIA delegate with suitable delegation authority will be required to review the assessment and make the decisions to approve the funding.

Participants should have the smallest possible number of clear and consistent touchpoints throughout the assessment process. Needs Assessors should be part of a multidisciplinary team to allow them to access additional and more senior expertise for more complex support needs. This should occur through the single lead Needs Assessor to prevent handovers.

The NDIA Needs Assessor should be employed directly by or contracted to the NDIA. They will make decisions as delegates about how government funding is being used and must be accountable for this.

We recognise that transition to this new assessment framework will require a significant workforce transformation for the NDIA. However, without the high levels of training, skill and experience necessary to deliver this key reform, the disability community will not develop trust in the ability of NDIA Needs Assessors or the reformed pathway as a whole.

Moreover, accurate assessments of need are the bedrock of an equitable and sustainable scheme and so this is an essential investment in the future of the NDIS.

An assessment that works for early intervention

The NDIS must develop an approach that generates leading practice in early intervention, which includes adaptive, multidisciplinary practice, wrap-around support and more effective monitoring of outcomes. Participants accessing the NDIS through early intervention (who are not children) mostly have a newly acquired disability, progressive conditions or episodic conditions. The needs assessment process must work for them.

With respect to setting a budget for these participants, the process should include skilled assessors who understand and are trained in early intervention and progressive and episodic conditions. They should also have access to clear, usable guidance on best-practice for both progressive and episodic conditions (including centralised experts who can provide specialist advice to the assessor). There will be a children-specific assessment approach for those under the age of 9 which is described in the children's section (see Section 5.3.8).

These assessors must have the knowledge and empathy to recognise and respond appropriately to intersectional needs and multiple disabling conditions. They must possess the skills to clearly assess the need for early intervention supports (such as capacity-building supports for maintenance or limiting loss of functional capacity), as well as support needs that may not be related to early intervention.

<u>Method for determining a reasonable and necessary budget based on a needs assessment</u>

Once a needs assessment has been completed, there must be a robust methodology to convert the assessment findings into a whole-of-person reasonable and necessary budget. The accuracy and acceptability of the budget setting is obviously critical to the success of our proposed changes.

Two main approaches to assessment-informed, whole-of-person budgets are used internationally and across other service systems in Australia:

> **Individualised budgets**, developed through either an item-based approach or a formula-based approach. An individualised methodology results in each person having a unique and distinct budget. For example, 600,000 participants would mean there can be up to 600,000 unique assessment informed budget amounts.
>
> **Non-individualised budgets**, developed primarily through a levels-based approach. Non-individualised methods involve separating a population into different groups based on levels of defining attributes (e.g. need, life stage, and circumstance). Each group is associated with a pre-defined budget amount, so that each person assigned to a level is assigned the same budget. A well-known example of this approach is the Aged Care Home Care packages in Australia, which of course is very different to the NDIS.

Figure 43: Summary of budget setting approaches, benefits and risks

Individualised budgets, developed through either an item-based approach or a formula-based approach	
A) Item-based: Involves identifying support items with an assessment and then identifying the level of support required for the item (e.g. hours). The level of support is then multiplied by agreed prices to determine the budget amount.	
Benefits: • Is individualised. • Ability to reflect very specific needs communicated during the assessment. • Less change from the current approach, which may help with transition.	**Risks:** • Can require a more intensive assessment to explore all possible options. • There is a higher reliance on the assessor to make judgements. • High reliance on validity and reliability of the assessment / information gathering process.
B) Formula-based: Involves identifying which characteristics of an individual (variables) contribute to support costs and the magnitude of the impact. This yields a formula that can assign a budget amount based on information about individuals.	
Benefits: • Is individualised (but is predicting support needs rather than asking the individual). • Complexity makes it harder to skew responses. • Promotes flexible use of funding as it is not tied to specific support items (as item-based is).	**Risks:** • Harder to explain and harder for members of the community to understand. • Can be overly dependent on historical analysis to determine the formula. • Very high reliance on validity and reliability of the assessment / information gathering process.

Non-individualised budgets, developed through a levels-based approach	
C) Levels-based: Involves separating a population into a small number of different levels based on defining attributes (e.g. level of need, life stage, and circumstance). Each level is associated with a budget allocation, so that each person assigned to a level is assigned the same budget.	
Benefits: • Is simple to communicate and understand. • Supports models where the service response should be more defined or specified. • Reduced specificity of the output lowers reliance on assessment accuracy.	**Risks:** • Doesn't create an individualised-budget (though it does involve individual assessment of need). • Is only suited for narrower / specific populations where need and preferred service response is more homogenous.

We have heard a strong preference from the disability community for individualised budgets to continue. This could be delivered through either an item-based or formula-based approach.

We agree that an item-based approach would be the most suitable approach to implement the new needs assessments. As outlined above, we found benefits in choosing an item-based approach because participants and families can convey very specific needs through the assessment. This would also be most similar to the current planning processes.

The main risk identified in Figure 43 is that an item-based approach requires a more intensive assessment process than the alternative approaches. However, we believe an approach that makes an investment in understanding the holistic needs of the individual is the right approach. This will help ensure that there is appropriate time spent understanding the participant, their strengths, goals, circumstances and support needs. This is better than an approach that has a risk of being conducted too quickly.

A way to mitigate the impact of longer assessments is to allow budgets to be valid for multiple years and to provide far more flexibility in the budget. This would allow participants with stable needs to choose to have longer budgets and less frequent needs assessments. This means they may need to do a more rigorous needs assessment, but less frequently than currently occurs with annual plans.

We also recognised that community trust in the use of predictive tools by government is low. Combined with a current low level of trust between the NDIA and participants, this means a formula-based approach is very unlikely to be acceptable in the near future. It would also be the largest change from the current planning process and most complex for participants and families to understand. These factors mean it is unsuitable.

The benefits and risks of a potential levels-based approach with young children is considered in more detail Section 5.4.3.

> **Box 22: Guidance on implementation of budget setting processes**
>
> Building on feedback from the Review's participatory engagement process and funding allocation experts, we have developed the considerations below to guide the NDIS Experience Design Office in its design of the budget setting process.
>
> The Co-Group has developed its own distinct set of principles and considerations that are relevant to the implementation of budget setting. The *Co-Group Feedback to the NDIS Review Panel* is provided at Appendix B.
>
> - Transparent budget decisions: Budget calculations are transparent with sufficient information on how decisions are made, so that participants understand how their budget was constructed, and know how to appeal decisions.
> - Needs-based budgets: The NDIA should use the information they gather about people's needs including from self-assessment, trusted professionals, family and/or supporters, and outcomes of the need assessment to determine a budget at a whole-of-person level. The way

the NDIA decides the level of support for a participant must be applied consistently and lead to funding that enables them to meet their needs.

- Flexible budgets: The needs assessment should be linked to more flexible budgets. Having more flexibility with how the budget can be used means that funding can be more responsive to need between assessments. It should also mean assessments are only needed when the change in need or circumstance is larger and can't be managed within the existing budget.
- Change in need or circumstances: Where a participant's needs change significantly within a budget period, which cannot be met within the more flexible budget, there is a responsive, simple mechanism to trigger a targeted needs re-assessment. Priority should be given where delay is likely to place participants at risk. There should be a triaging of assessment requests to ensure those at risk are supported as quickly as possible (including the potential for a needs assessor to recommend funding of supports critical for safety and wellbeing using a rapid needs assessment process). This triaging approach should be available to all participants at times of crisis or unexpected life transition.
- Opportunity to review needs assessment: Participants and their nominees have access to the outputs of the needs assessment before it is finalised to enable provision of any missing information and correction of factual inaccuracies before it is used to set a budget.

Box 23 details three international examples of individualised and non-individualised assessment informed budget setting processes to illustrate how each works in practice. These provide starting points to learn from, particularly issues with the implementation in other jurisdictions. The Review is not recommending any needs assessment for immediate introduction.

Box 23: Examples of assessment-informed budget setting processes

Item-based approach: Oregon Compass Project (Adult Needs Assessment)[648]

- The Oregon State Government uses an item-based approach to budget setting as part of its Compass Project. Further information is available here.
- The Compass Project uses an Adult Needs Assessment and Children's Needs Assessment to determine the support needs of children and adults with intellectual and developmental disabilities. It is also used to identify potential risks and produce a risk report.
- Assessment process:
  - o The Adult Needs Assessment is completed by a trained assessor, who asks a series of questions about a person's abilities and support needs.
  - o The assessor considers the information provided by the individual and people in their life who can provide additional context and information.
  - o To determine an individual budget, the assessor inputs responses collected into the assessment tool which generates specific hour amounts of support for particular support items. The support hours are tallied to produce a monthly budget allocation.

Visual example of how specific items of support can be built up into

AMBULATION/MOBILITY IN THE HOME AND COMMUNITY		*2:1 Review*
This section assesses the individual's physical ability to move around in the individual's home and community with or without mechanical aids. Choose the option that most accurately reflects the supports required by the individual, which are not due to behaviours.		
○ **Independent:** The individual can move about in familiar surroundings without assistance from another person with or without mechanical aids.		
○ **Partial Assist:** The individual is dependent on assistance from another person for some aspect of ambulation/mobility.		
○ **Full Assist:** The individual is dependent on assistance from another person for all aspects of ambulation/mobility.		
● **Two-Personal Assist:** The individual requires assistance of two people for all aspects of ambulation/mobility. *Documentation required.*		
In Home Needs Summary - Adult		
Name of Individual:		Date of Birth:
Date of Assessment:		Age:
	Assessed Hours per day	**2:1 Review?**
ADL/IADL Hourly Supports	1.00	Yes
Behaviour Hourly Supports		No
Medical & Safety Hourly Supports		No
Night Time Hourly Supports		No
		No
Daily Average Attendant Care Hours	1.0	
Monthly Attendant Care Hours	**30.41**	
	Assessed Hours for Plan Development	**Adjustments for 2:1**
Start Date for Services:	**Total Approved Monthly Attendant/Relief Care Hours:**	**30.41**

Behaviour-Revised (SIB-R) Assessment)

- The Idaho State Government uses a formula-based approach to budget setting as part of its Developmental Disabilities Waiver Program. Further information is available here.
- Idaho Medicaid uses the Scales of Independent Behaviour-Revised (SIB-R) to learn about support needs and inform eligibility. They are transitioning to the Supports Intensity Scale.
- Assessment process:
    - The assessment is completed by a trained assessor, who asks a series of questions relating to adaptive behaviour and maladaptive behaviour, including functional independence in school, employment, and the community settings. The Adaptive Behaviour items are rated based on the extent to which the individual performs a task completely and independently. The Problem Behaviour scale is rated based on frequency and severity of each behaviour.
    - The assessor considers the information provided by the individual and people in their life who can provide additional context and information.
    - To determine an individual budget, the assessor inputs information and responses collected into the assessment tool and an algorithm is used to generate individual budget.

A visual example of how a formula can be used to

The regression model equation is:
$$Y = b_1 \cdot x_1 + b_2 \cdot x_2 + b_3 \cdot x_3 + b_4 \cdot x_4 + b_5 \cdot x_5 + b_6 \cdot x_6 + b_7 \cdot x_7 + b_8 \cdot x_8 + b_9 \cdot x_9 + b_{10} \cdot x_{10} + b_{11} \cdot x_{11} + b_{12} \cdot x_{12}$$
Where:

Y = Calculated plan amount (annual)	Model coefficient waiver	Model coefficient non-waiver
x_1 = Waiver Status	25,628.54	6,211.20
x_2 = General Maladaptive Index (GMI*var)	-148.68	-57.16
x_3 = Mental Retardation	5,879.85	0
x_4 = Autism	4,389.63	0
x_5 = Cerebral Palsy	5,573.41	0
x_6 = TBI	2,672.81	0
x_7 = High Risk Behaviour	2,139.01	0
x_8 = Nursing		
Nursing monthly	39,855.20	0
Nursing weekly/daily	61,204.97	0
x_9 = Level of Support Needed	908.68	0
x_{10} = Transportation	Imputed $	Imputed $
x_{11} = Sum of Bathing, Grooming, Dressing, Toileting and Feeding (x*var)	167.26	458.47
x_{12} = Sum of Laundry, Housekeeping and Meal Prep (x*var)	0	358.20

The North Carolina State Government uses a levels-based approach to budget setting for the Service

- North Carolina Innovations uses the Supports Intensity Scale to identify what help a person with intellectual or developmental disabilities needs to do the same things that others do.
- Assessment process:
  - The assessment is completed by a trained SIS interviewer who asks a series of questions to understand the individual's needs to determine the level of support required. The assessor considers a number of areas, including home living, community living, and health and safety supports, as well as exceptional medical and behavioural support needs.
  - The assessor considers the information provided by the individual and people in their life who can provide additional context and information.
  - The assessment generates a support intensity score that allows the individual to be placed into a support level, including their circumstance. The budget is predetermined for each level based on a predicted service mix and cost of meeting the need of individuals within the level.
  - The levels are intended to cover base budget services. They may also be eligible for a small number of 'add-on' supports in addition to the budget set by the levels.

A visual example of a levels-based

Support level category	Adult residential	Child residential	Adult non-residential	Child non-residential
A	$65,000	$60,000	$20,000	$7,000
B	$69,000	$62,000	$22,000	$9,000
C	$72,000	$67,000	$24,000	$11,000
D	$75,000	$72,000	$26,000	$13,000
E	$80,000	$75,000	$28,000	$15,000
F	$85,000	$85,000	$33,000	$20,000
G	$90,000	$90,000	$38,000	$25,000

How participants are allowed and supported to implement their budgets

Greater flexibility in how the budget can be used

Delivering a more needs-based NDIS requires reform not only to how budgets are determined, but also to how they can be used. If budget decisions are to be based on need, it makes sense that participants should be given flexibility to use that funding in a way that meets their need.

This would mean budgets are more adaptable as needs change over time. Allowing flexibility in ways that funds are spent is a hallmark of a system that strives to be responsive to individuals' unique and changing needs.

More flexible budgets mean there should no longer be an arbitrary barrier between "Core" and "Capacity Building" funding allocations in the future. These categories should be combined. The overall, whole-of-person NDIS budget of the future should be simpler. It should consist of:

- A flexible budget
- A housing and living budget (if required)
- Stated supports for assistive technology, equipment, or other one-off capital costs (Figure 44).

The housing and living budget includes stated funding for Specialist Disability Accommodation, home modifications, medium-term accommodation and 24/7 living supports. A participant should be allowed to use their flexible budget for housing and living supports, but not vice-versa. This is to ensure they have the funds for this critical support for the life of their plan. Further detail on the housing and living budget is provided in Chapter 3.

There will continue to be a need for stated items within the overall budget. This will primarily be the case for housing and living supports, other high-cost or bespoke capital items that will likely require a separate process of quoting before allocating funds. Funds of this type must be used for the specific purpose for which they have been approved. The additional controls on funding for housing and living supports are to make sure that participants have those needs met and are never in a position of having to forego a housing or living support.

These new arrangements do not mean participants can use their NDIS funding to purchase anything. Participants would still be required to use their whole-of-person budgets in ways that are consistent with the objects of the NDIS Act and clarified Rules. This will require greater clarity on expenses that are not covered by the NDIS, such as ordinary living expenses. Navigators should assist participants to understand more easily what is and is not allowed.

Figure 44: Comparison of current and future support budgets
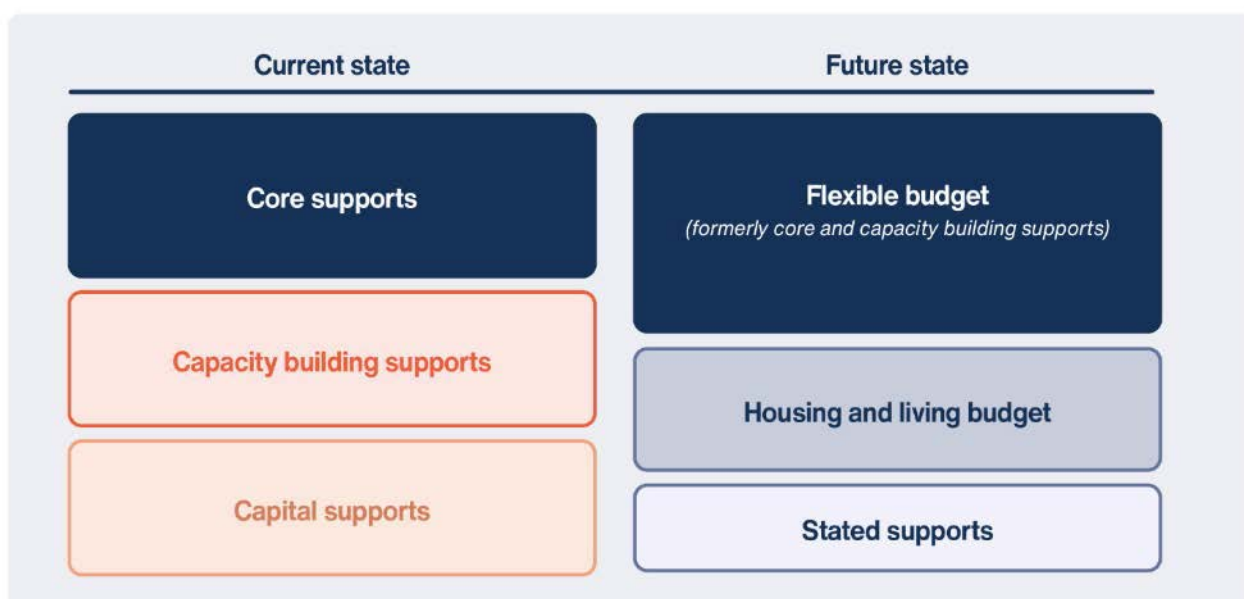
Flexibility of funds should apply within the designated period of the allocated budget. Flexibility of funds cannot apply to different, successive budget periods. For example, if a participant spends less in the designated period than funds allocated to that budget, those unutilised funds cannot be carried forward into the flexible budget of the next period.

This must never mean, however, that unutilised flexible funds in one budget period will adversely affect the flexible funds allocated to the next budget period. Participants will not 'lose' funding for stated capital supports that it has not been possible to utilise within the budget period. For example, if a participant was approved to purchase a particular item of equipment, assistive technology or a home modification but could not make the purchase within the budget period, the approval for stated capital item would automatically roll-over to the next budget.

The NDIA should communicate with participants and families to clarify this and regularly publish data on budget reviews and prior year budget utilisation to give them confidence this is the case.

A local navigation function to support participants

A key element of the proposed approach is ensuring participants have much more support from a Navigator to assist them with a plan of action to use their budget and support implementation of that plan. This is outlined in more detail in Section 3.1.6.

A critical role of Navigators will be to assist participants to decide how best to use their whole-of-person funding and develop a plan of action that aligns with their needs and the objects of the NDIS Act. This plan of action will help participant to understand what they can purchase. The Navigator will also help by providing options on how the participant may choose to use their funding to support their disability-related needs. Those supports could include more innovative ideas that have led to good outcomes for participants with similar support needs.

They should also support participants to connect with local providers and offer advice on what participants should consider when choosing between different providers. However, Navigators should never offer recommendations about specific providers.

The Navigator should also provide information and advice to participants on making connections in their local community, as well as links to mainstream and general foundational supports (e.g. peer groups). The Navigator should also assist participants as their needs change or there are changes in the availability of providers.

We acknowledge that many participants use the brief narrative detail included in current plans to guide how they use funding and/or identify whether there is enough funding to purchase particular supports. More flexible budgets will mean this narrative doesn't exist within the budgets as is currently the case (this is to allow funding to be used in more flexible ways). However, there will be significant information available from the needs assessment, including a detailed needs assessment report provided to the participant. This, along with support from the Navigator, will give far more guidance on what support needs were identified and how those supports might be met. The detailed needs assessment report will be made available to the Navigator as part of developing the plan of action (with consent).

Renewing the trust base to guide the NDIA approach to overseeing budget use

Giving participants multiple ways to use funding and providing people with choices as to how to use consistently determined needs-based funding is a key part of our reforms. This requires a more trust-based approach to overseeing budget use by the NDIA.

Shifting to a trust-based approach of providing participants with the information and support they need to make choices that work for them would be a significant positive change. Participants and Navigators would be able to collaborate to get the best value out of a budget by making good use of local supports and understanding what types of supports lead to better outcomes. This approach would encourage participants to utilise funding effectively and efficiently to best meet their needs.

Participants should also be provided with clear and simple guidance on how to determine if a support is appropriate to access through their budget. We do not propose changing current NDIS Rules which include that supports must be related to the person's disabilities, be legal, not replace supports provided by other government agencies and not cause harm or put a person at risk. If participants are unsure if they can purchase a support, they would be able to get help from their Navigator to better understand the requirements. It is important to note that, the new approach to needs assessment should take account of all of people's disabilities and end the current focus on primary and secondary diagnosis.

The NDIA would still need to ensure that funding is being used appropriately. We are recommending that all payments be visible through a real-time claims management system (see Action 10.3). This should be complemented by a compliance model that assumes most participants and their nominees will seek out supports that are likely to work for them and are doing the right thing.

Where the NDIA is concerned or is aware funding is not being used appropriately, compliance should be encouraged through a graduated approach to monitoring and enforcement (Figure 45). It should be made clear to participants that if they are trying to do the right thing, they will not be penalised for genuine mistakes or errors. This is a critical part of improving trust between the NDIA and participants.

Figure 45: Overview of the approach to compliance (adapted from the Australian Taxation Office compliance model)[653]
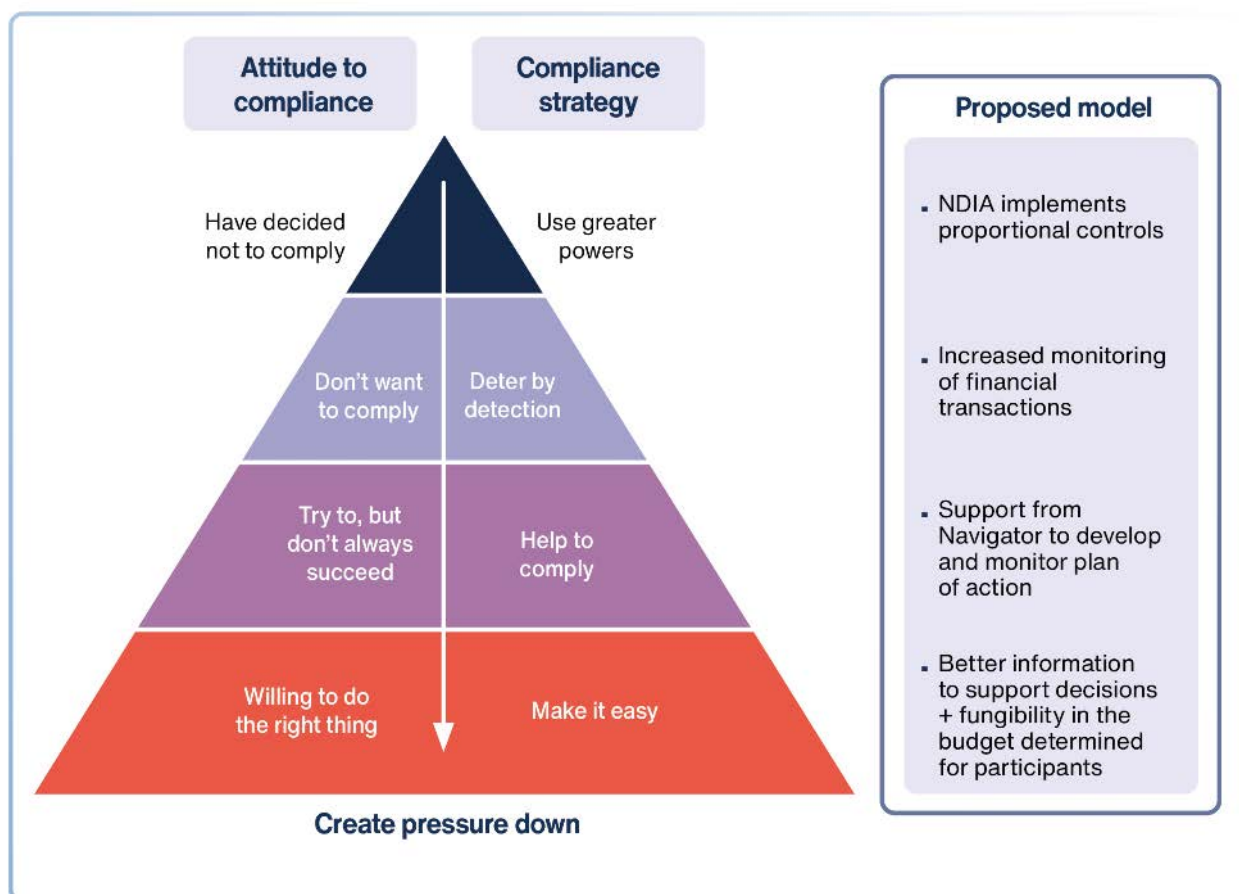
2.2.3. How our proposals would work

The case studies below provide further detail on how the changes described above will work in practice. The case studies highlight differences between how the current planning process works and how the future budget setting approach would work for different participants.

Case study 7: Henry, 35 years old, diagnosis of Intellectual Disability, Autism Spectrum Disorder and Epilepsy

Henry lives with his mother and father in a very large regional centre. His parents are now in their late 60s. He has had an NDIS plan since the scheme rolled out in his area.

His primary disability in the NDIS system is Intellectual Disability, with a secondary diagnosis of Autism Spectrum Disorder.

His mother has been appointed as his NDIS Nominee. Henry's plan is currently managed by the NDIA.

<u>Current experience</u>

- Henry's plan has been rolled over the last two years. His mother had agreed to a plan rollover as she was happy with the funding level they had and had heard of other participants who lost funding and support during a review.
- His mother wants to talk about a new support item so agrees to schedule a plan review, even though Henry's needs have not significantly changed. The one change they would like is funding for a home modification in order to install a security camera and intercom system. Henry has been anxious about people visiting his home and his psychologist has recommended a camera be installed to help Henry with his concerns about visitors.
- Henry, his mother and his support worker attend their plan review meeting at the NDIA office.
- They have had a new planner every year. They have never met this planner and Henry is uncomfortable meeting new people. He does not like being in a small, unfamiliar room. This makes him anxious and he leaves with his support worker while his mother completes the meeting.
- The planner asks about an underspend in Henry's plan. Henry has been unwell with a respiratory infection in the past 6 months, so has not used much of his capacity building budget. This includes $5,000 for speech therapy, which Henry's family had to argue to have included for multiple plan reviews. His mother is very anxious about this funding being removed as Henry really needs speech therapy in the next 12 months. She insists on its importance but is not sure that the planner understands or whether she needs to provide more evidence. The planner makes notes and moves the meeting on.
- Henry's mother asks for additional funding for a home modification. To support the request, she presents a report from Henry's psychologist noting that a camera and intercom system would help with Henry's anxiety, and enable him to interact safely with visitors and support workers. He has locked support workers outside the house when his parents have been away and they are worried about leaving the house. Henry's mother had to spend some of his budget to prepare this report. She has been told by Henry's specialists that the system will help with his anxiety, but it costs more than she thinks she is allowed in his current plan for assistive technology, and she is anxious not to make the wrong decision.
- The planner is not sure if something like this can be funded. The planner doesn't think it does not seem relevant to his intellectual disability and suggests that is an everyday cost as many people without disability may use security cameras at home. She cannot find any examples of funding similar supports for people with Henry's diagnosis on the intranet. She makes a note to check with her manager and begins to wrap-up the meeting.
- The planner asks if there is anything else to cover. Henry's mother says no even though she has been worried about what will happen as she and her husband get older. She has started thinking about whether Henry should live somewhere else but is afraid that the planner will want him to move to a big group home. She decides to raise it next time when she is better prepared. She has heard that Henry will need a goal in his plan to allow the funding and does not feel confident in asking without risking being pushed into a living situation that Henry doesn't want.

- Henry receives his next plan, and it has reduced funding for speech therapy and the camera and intercom system has not been included. He receives a template set of reasons stating that the supports are not considered reasonable and necessary, but they have no way of contacting the planner to understand why the evidence provided was ignored.
- They begin a section 100 review to contest the decision, and all their energy goes into collating evidence for the review. There is little time to think about possible future accommodation options or other plans for Henry's future.

Future experience

- Helen lives in the local area and has been assigned as Henry's NDIA Needs Assessor. With Henry's mother's consent, she receives all of Henry's past plans, his most recent functional capacity assessment and other evidence submitted in previous planning meetings. With help from his mum and his support workers, Henry also uses the new NDIS Participant Portal to upload a video to talk about his ambition to one day to work on a construction site.
- There are inconsistencies in the information on Henry's file. Helen prepares detailed notes to pull all of the information together. This starts to give her an idea of where to start the needs assessment with Henry and where she'll need to ask most of her questions.
- Henry and his mother ask Helen to meet them at their house. The first assessment meeting is spent talking informally and allowing Helen to interact with Henry in the home. Henry shows Helen his Meccano set and movie collection, which allows her to find out more about his interest in construction and what he likes about film.
- Henry becomes agitated after 30 minutes, so Helen asks Henry if he would like her to ask his mother some questions while he takes some time to himself. Henry agrees and Helen gives him some space while she speaks with his mother.
- Helen doesn't have a lot of direct experience with Epilepsy (she is a trained speech pathologist) so she checks with another NDIA Needs Assessor whether her assessment is adequately accounting for his Epilepsy and needs associated with anxiety. With his consent, she also talks to Henry's psychologist to get a better picture of how his anxiety has fluctuated over time.
- Helen returns to Henry's home for the second assessment session, and shares with Henry and his mother how she has assessed his need so far across each domain. She checks her assumptions with them and adjusts the assessment during the conversation as she finds out more about Henry.
- Helen talks to Henry about what support he needs to make decisions about his life. He also talks to Henry and his mother about the possibility of setting up a circle of support that could assist Henry, particularly as his parents are getting older.
- Helen had wanted to talk to Henry and his mother in the first session about his living situation but had assumed this would be sensitive topic. She left these questions until she had started to build some rapport with Henry and his mother.
- Henry and his mother are happy for him to continue living at home but will want to explore options in the future. It's clear to Helen that funding modifications to the family home would

mean that Henry can continue living in his family home. This makes sense for everyone for now.

- Helen lets them know that they can ask for a new needs assessment when they are ready to explore other housing options. She makes a note for his Navigator to set up a discussion with a housing and living expert.

- Before she leaves, Helen shows Henry and his mum the notes she has made on her iPad during the assessment. It has all of the detail they have been discussing against different activities and domains. Henry and his mum have another chance to make sure they weren't misunderstood and key information has been written down correctly.

- Helen then completes the budget calculation based on the completed needs assessment, including funding for decision-support and funding for assistive technology to assist Henry's in being more independent at home.

- Helen shares the completed needs assessment with Henry and his mum on the NDIS Participant Portal, along with the budget.

- The budget contains an overall sum in the flexible budget as well as a clear stated amount for the assistive technology required. Although the budget is different to his previous one, Henry's mum can see that his needs are accurately reflected. She is anxious that he may not have enough funding and that she may have to provide additional support, but agrees to be connected with a Navigator to help work through what is possible before she asks for a review.

- Stan is Henry's Navigator. He helps Henry and his mum to make a plan of action based on Henry's needs assessment. They agree to prioritise Henry's long-term goal of being able to work at a construction site and talk about meeting with one of Stan's colleagues who is a housing and living expert in the future.

- Stan helps Henry to connect with a support worker is a similar age to Henry and is able to help him explore his interests. Being able to use funds flexibly allows Henry and his mother to explore new ways for him to develop his skills.

- Stan also connects Henry with a local community group that supports people with autism to connect with other people with similar interests. Stan connects Henry and his family to an organisation that can assist with setting up and facilitating a circle of support. They agree to check in again in 6 months' time to make sure Henry is getting what he needs.

- Henry's mum realises that they didn't talk about the extra support Henry would need traveling to and participating in the community group, but Stan reassures her that it is ok to use some of the flexible budget for this.

Case study 8: Rae, 45 years old, multiple sclerosis

Rae has been diagnosed with multiple sclerosis (MS). She has a job and has been independently living in an apartment since she was younger. Her friendship group are very close and visit each other often, but she doesn't have any family who live near her.

Her condition is deteriorating and her specialist has helped her make a successful access request under section 25 (early intervention requirements) of the NDIS Act. Rae is new to the NDIS and has never had disability supports before. This is her first plan in the NDIS.

Current experience

- Rae finds an online community of other women with MS, where she learns about the supports others have received and the kind of language she needs to use to get them. She is unsure what to expect from the process and reads others' stories about how difficult it can be to get the right supports.
- She fills out the NDIS planning booklet and gathers reports from her specialist for the supports others tell her she needs to help adjust to her new disability.
- She meets with her Local Area Coordinator (LAC) who talks through her requests and specialist reports with her. The LAC approves the supports for which she has specific requests but doesn't suggest any additional supports. The LAC sends their report to the NDIA delegate in charge of Rae's plan. The approved is sent to Rae two weeks later.
- Rae receives her plan, and can see it includes some of specific supports she requested, as well as some things not included and others included but the numbers don't make much sense to her. Rae is confused about what is included.
- She talks to her Local Area Coordinator, who cannot clearly explain why different supports have been funded or not funded. Rae feels sad, but thinks it is too hard to keep trying to figure out what has happened. She's also worried about losing what has been included if she asks for a review.
- She begins physical therapy but soon realises there is a group class at her gym that would complement her therapy and is a lot cheaper than therapy. This would help her plan stretch further and she's already worried that there is not enough in her plan for the full year.
- Rae tries to call her LAC but doesn't have a direct number. She calls the organisation's reception and after repeating her details to someone new, she receives a response that group gym classes are not funded by the NDIS unless they are disability specific groups, but she doesn't get any guidance on what else to do instead.
- She is really worried that she cannot get the right support to help slow progress of her condition and whether her plan will be enough for the rest of the year.

Future experience

- Kwang is Rae's Needs Assessor. He can see the specialist reports Rae submitted as part of her access request, including the information her specialist provided on the kind of supports that would help slow the progression of Rae's condition. Kwang also has access to clear guidance

- on best practice for early intervention for multiple sclerosis, and is a trained occupational therapist.
- As requested by Rae, they meet at the local NDIS Office and have a coffee. Kwang asks Rae about her aims for the next few years, her job and her support network. Rae is very clear on what she wants to achieve and trusts her specialist's recommendations, so the meeting only lasts an hour. Kwang returns to his office to complete the assessment and schedules the next meeting with Rae.
- Kwang talks through the completed needs assessment with Rae at their next meeting, and can quickly provide her with a flexible budget, with clear guidance on what has been included for home modifications. He introduces Rae to a Navigator who can help her create an effective plan of action for early intervention.
- Joe is Rae's Navigator, he has a family member with lived experience of MS, and has supported other participants with multiple sclerosis.
- Rae has a clear picture of her goals and her plan of action and Joe records this, and connects Rae to a peer support group. Rae asks Joe if he can check in with her after 3 months to understand progress and help adjust her supports if needed, depending on changes in her condition and circumstance. Rae and Joe complete an outcomes assessment at each check-in.
- Rae is able to spend less on therapy than she expected, and uses some these savings on specialised cooking utensils and other assistive technology that can make her home safer as her condition progresses. She knows spending her budget in this way will make things easier for her later.
- After 2.5 years, Rae's needs change as her condition progresses. She is well prepared but her needs are changing. Joe shows her how to request a needs re-assessment and explains the next steps once the NDIA contact her to schedule an assessment.

2.2.4.   Action & Implementation Details

Action 3.3: The National Disability Insurance Agency should change the basis for setting a budget to a whole-of-person level, rather than for individual support items.

This would require Australian governments agreeing to re-define reasonable and necessary in the *National Disability Insurance Scheme Act 2013* and NDIS Rules as the total amount of funding determined to meet the support needs of a participant. The whole-of-person reasonable and necessary budget should be based primarily on supports needs and intensity, rather than functional impairments. Focusing on support needs is intrinsically more person-centred and strengths based than the functional assessments used currently. Focusing on the whole person, their circumstances and their support needs would also end the current unhelpful and inappropriate focus on establishing a primary or secondary disability. A whole-of-person budget should be sufficient to cover the amount and type of support needed to

enable the participant to participate in an inclusive life. This should be determined through a structured needs assessment (see Action 3.4).

Implementation detail:

- Following the development of the needs assessment process (see Action 3.4), the National Disability Insurance Agency should use the support need determined by the assessment process as the basis for setting a reasonable and necessary budget.

  - This should involve the NDIS Experience Design Office (see Action 24.3) developing a method to convert the outputs of the assessment process (processes) to reasonable and necessary funding amounts.

- The Department of Social Services should develop and bring forward proposed amendments to the NDIS Act and Rules to enable the implementation of the proposed needs assessments, including making a reasonable and necessary determination at a whole-of-person level rather than for individual support items and creating assessment-based budgets (see Action 3.4).

Action 3.4: The National Disability Insurance Agency should introduce new needs assessment processes to more consistently determine the level of need for each participant and set budgets on this basis

This should support the allocation of a reasonable and necessary budget at a whole-of-person level (see Action 3.3). This would require structured, reliable and valid assessment processes to enable Needs Assessors to accurately identify support needs and intensity. This should also include an assessment of what risks might be present in the participant's life and what safeguards could be put in place in response.

The assessment should enable the Needs Assessor to identify types of support needed, frequency, and any one-off or time limited support required. The Needs Assessor should be able to understand how different support types combine to create a package that makes sense for and meets the needs of a person. The Needs Assessor should be a representative of the National Disability Insurance Agency (staff member or contractor). To deliver this, a significant investment should be made in the time spent on each person's assessment and the experience, training and qualifications of the Needs Assessor.

The total cost of supports recommended by the Needs Assessor should be translated into a budget that can be used more flexibly by the participant to meet their needs (see Action 3.5). Budgets should be able to be multi-year where the Needs Assessor has determined with the participant that this is appropriate. Re-assessments should ideally be scheduled to align with key life transition points where relevant. The budget would be indexed at 1 July each year

following price reviews. Existing support needs assessments should be tested with the groups and disability types they have been validated for to inform the design of the new budget setting process.

These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8).

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should be responsible for the design, testing and refining a customised needs assessment that can determine the holistic needs of a participant, including consideration of circumstance and life stage. This should involve:

  - A transparent and rigorous process to design and test the assessment prior to introduction, including:

    o Working closely with participants, families, representative organisations measurement experts, and health professionals to design the assessment process and the approach to validation.
    o Establishing a mechanism to regularly share the direction and progress of the design process for stakeholders who are not directly involved in the design process.
    o Learning from the findings of the Joint Standing Committee on the National Disability Insurance Scheme inquiry into Independent Assessments and a commitment to Recommendation 6 from the same inquiry that all assessment tools for the purposes of informing funding decisions should be subject to deep engagement and testing before implementation.
    o Establishing distinct assessment pathways and supporting infrastructure to enable the assessment process to be tailored to the unique circumstances of participants.
    o Determining Needs Assessor workforce requirements to deliver the assessment, including mandatory training, experience, or skills. Noting that allied health professionals, social workers and youth workers with disability training and experience, are likely to have the most suitable backgrounds to be conducting assessments and making decisions based on need. However, formal qualifications may not be available in all circumstances, given other important requirements such as culturally appropriate backgrounds and lived experience of disability. There should be careful consideration of exceptions to these requirements.

  - Developing an assessment that:

    o Can deliver validity, reliability and consistency across different groups.
    o Measure support needs and is mapped to the World Health Organisation International Classification of Functioning, Disability and Health.

- o Is suitable for a range of age groups and disability types (including multiple disabilities, progressive and episodic disabilities), noting that it is proposed that a distinct assessment approach is used for children.
- o Is able to be proportionate to an individual's level of need and to ensure the rigour of the assessment reflects need and the size of the budget.
- o Can facilitate the automatic transfer of data from the access pathway and any previous assessments of need, as well as data from other service systems where relevant so participants do not have to repeat information already provided to government (subject to consent and approval).
- o Can provide an output directly to participants as a record of how they were assessed and the findings of the assessment.

- The National Disability Insurance Agency should begin implementation of the assessment process following rigorous testing and refinement and once Disability Reform Ministers have endorsed the assessment, budget setting methodology and proposed implementation approach.

- The National Disability Insurance Agency should:

  - Undertake a review of operating guidelines and internal guidance materials to determine the changes required to implement the proposed needs assessments and change to reasonable and necessary determinations.

  - Establish a Needs Assessor workforce of individuals suitably skilled, experienced and trained to undertake the assessment. The minimum requirements of the Needs Assessor workforce should reflect the distinct assessment pathways and the different circumstances and requirements of participants.

    - o All Needs Assessors must be able to deliver culturally safe assessments for First Nations and culturally and linguistically diverse participants. However, the development of a distinct and targeted workforce of First Nations and culturally and linguistically diverse identifying assessor should also be prioritised.

  - Work with other Australian Government agencies, particularly the Department of Health, to establish a consistent approach to engaging suitability skilled and trained Needs Assessors across the Commonwealth care and support sector. This should recognise the distinct skill and training requirements of Needs Assessors to be suitable for the NDIS, while seeking to achieve benefits of scale and preventing competition for skilled Needs Assessors between Commonwealth service systems.

Action 3.5: The National Disability Insurance Agency should allow greater flexibility in how participants can spend their budget, with minimal exceptions

The budget should consist of a flexible budget, a housing and living budget, and stated supports for assistive technology, equipment, or other one-off capital costs. The flexible budget should include funding for supports formerly known as core and capacity building supports.

The housing and living budget should include Specialist Disability Accommodation, home modifications, medium-term accommodation and 24/7 living supports. A participant should be allowed to use their flexible budget for housing and living supports, but not vice-versa. This is consistent with the increased focus on a needs-based approach.

Participants should be supported by their Navigator (see Recommendation 4) to decide how to best use their funding and develop a plan of action in line with the objects of the *National Disability Insurance Scheme Act 2013*. Aligned to more flexible budgets, NDIS Rules would also be developed to better define what 'ordinary living expenses' are.

Implementation detail:

- The NDIS Experience Design Office should ensure the design of the needs assessment and budget setting process (see Actions 3.3 and 3.4) and the Navigator functions (Recommendation 2) allow for the provision of flexible budgets for participants as outlined above.
- Following the development of the needs assessment, the National Disability Insurance Agency should allow flexibility to participants to use their reasonable and necessary budget in the way that best meets their needs where it is consistent with the objects of the NDIS and NDIS Rules. The exception to this increased level of flexibility is any reasonable and necessary funding allocated for:
  - Housing and living supports (including any funding approved for Specialist Disability Accommodation, medium term accommodation, and 24/7 living supports) (see Recommendation 8 for more detail).
  - Stated supports.
- As part of Action 3.5, the National Disability Insurance Agency should ensure their digital and service systems can support the provision of flexible budgets for participants as outlined above.
- The National Disability Insurance Agency should implement the above approach to flexible budgets as outlined above as soon as Disability Reform Ministers have endorsed the assessment process, budget setting methodology and proposed implementation approach. Once agreed, the flexible budget approach would be set out in NDIS Rules.

Action 3.6: The National Disability Insurance Agency should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support

All interactions with participants should be based on trust that they are using funding to improve their lives. The Navigator should be trained to support participants to make best use of their funding and make it easy for them to comply with rules through a clear plan of action and regular check-ins (see Recommendation 4).

The Navigator should also offer gradually increasing guidance and support where risks or minor issues are identified. Plans of action should be recorded in the same system as the needs assessment output (see Action 3.4), and fully electronic payments data (see Action 10.3) to equip Navigators with data to proactively identify risks and respond to issues. Where risks or issues are identified, the Navigator should have tools for mitigation and a clear escalation pathway.

As a last resort where a person has chosen not to comply with the rules or extreme risks of non-compliance have been identified, the NDIA should have transparent processes to implement proportional controls over a participant's budget. These should be codified in the NDIS Rules. This should be complemented by measures to better empower and support people with disability to make decisions about their lives (see Recommendation 5).

Implementation detail:

- The National Disability Insurance Agency should develop nationally consistent guidance to help participants find quality services and comply with rules about how they can flexibly use their funding. This should help participants and nominees comply with relevant NDIS Rules.
- In designing the Navigator and Specialist Navigator functions (see Recommendation 4), the NDIA should ensure there are appropriate tools available to Navigators that can be used to identify and mitigate risk and a clear escalation pathway to the NDIA where mitigation hasn't been effective.
- The NDIA should also endeavour to ensure that participants and Navigators have access to the same information (related to the participant) to foster greater transparency and trust in how this role may be delivered. This should prevent the Navigator acting on information about the participant that hasn't been shared with the participant (subject to privacy, consent and safety requirements).
- The NDIA should create and publish clear guidance on approval processes and tools available within the NDIA to implement proportional controls over a participant budget. To be used only where a person has chosen not to comply or repeatedly not complied with NDIS Rules or extreme risks of non-compliance have been identified. This should be codified in the NDIS Rules. The design of this approach must involve maximum transparency with and involvement of the disability community.

- The NDIA should ensure that training, practice standards and accountability mechanisms for Navigators (see Recommendation 4) support a workforce that is able to support participants, including those with cognitive disability and complex communication support needs, to develop, monitor and evaluate plans of action that help participants live valued and inclusive lives. This should include training on support for decision-making for participants with cognitive disability.
- As part of Recommendation 4, the NDIA should ensure Navigators are able to share good practice in supporting participants to develop plans of action, adapt those plans, identify and manage risks. The NDIS should play an on-going role in seeking out, sharing and requiring the uptake of good practice across all Navigators.
- The NDIA should work with the new National Disability Supports Quality and Safeguards Commission and the new NDIS Evidence Committee to ensure guidance and tools for Navigators are continuously updated based on the latest evidence.

Action 3.7: The National Disability Insurance Agency should reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes

The pathway should include a distinct access and needs assessment process to identify applicants who are likely to benefit from early intervention supports in the NDIS. This should include an agreed definition of 'likely to benefit' and clarification of when need can be appropriately met through the reformed foundational supports system. These should be clarified in the NDIS Rules. This should be linked to the outputs of a needs assessment that can allow applicants to be compared to their peers and identify appropriate service responses. Budget setting should be based on evidence of the frequency and type of early intervention support appropriate for the participant.

Early intervention participants should receive tailored support from a Navigator or Specialist Navigator. This Navigator should schedule check-ins and use mechanisms such as case conferencing to discuss progress, ensure service delivery is based on best-practice evidence and principles and adjust the approach where expected benefits are not being achieved.

Reassessments should be conducted biennially or at a frequency determined by the Needs Assessor to determine if there continues to be a need for and benefit from early intervention supports. These changes must be designed transparently with people with disability and other relevant experts (see Action 3.8).

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should design and test a reformed early intervention pathway that includes the following features:

- An access process that uses a needs assessment to inform the CEOs determination of whether a person:

  o Is likely to benefit from early intervention (section 25(1)(b) and (c) of NDIS Act).
  o Could have their need met through the reformed foundational supports system (section 25(3) of the NDIS Act).

- Budget setting based on evidence of the frequency, intensity and type of supports that are appropriate for the individual based on their needs assessment. Re-assessment of need should be conducted biennially or at a frequency determined by the Needs Assessor at the preceding assessment (reflecting the context and circumstances of the individual). Outcomes assessments that are separate from budget setting to ensure that participants feel that it is safe to share their progress and provide high quality information about the impact of the NDIS.

  - Support for the participant from a Navigator to develop a plan of action to use reasonable and necessary funding to access and adapt supports and combinations of supports that work for them. This should also involve regularly scheduled check-ins and mechanisms such as outcomes assessments and case conferencing to discuss the individual's progress and adjust the approach where expected benefits are not being delivered. Children under the age of 9 and their families would also be supported by a Lead Practitioner (see Recommendation 6) and participants with psychosocial disability and higher needs would also be supported by a Specialist Navigator (see Recommendation 7).

- The NDIS Experience Design Office (see Action 24.3) should ensure that:

  - The responsive access request process (see Action 3.2) can provide the necessary guidance to applicants and functionality to support the pathway described above.

  - The development of the needs assessment (see Action 3.4) can provide the functionality described above and includes consideration of the distinct support needs for some participants requiring early intervention (particularly those with progressive, degenerative or episodic conditions).

  - The design of the Navigator functions (see Recommendation 4) can provide the functions described above, including an approach for Navigators to be involved in the regular monitoring of the effectiveness of early intervention supports.

  - The National Disability Insurance Agency should establish dedicated workforce expertise to support the early intervention pathway. This workforce should be trained and resourced in understanding need and identifying what constitutes evidence-based early intervention supports.

  - The NDIS Evidence Committee (see Action 23.2) should provide advice to Disability Reform Ministers and the NDIA on effective early intervention practice and the early

intervention supports and intensities that are likely to be beneficial (or not) for particular groups, disability types, and circumstances. This should inform access and budget setting decisions and practice guides for early intervention.

- The NDIA should begin implementation of the reformed early intervention pathway once Disability Reform Ministers have endorsed the assessment processes, budget setting methodology and proposed implementation approach.

- Aligned with and supporting the new Rules, the NDIA should develop a comprehensive suite of operational guidance, resources and information to support community and family understanding of the reformed early intervention pathway.

3. Support people with disability to better navigate mainstream and disability supports

- We have heard from people with disability, families and the community that finding and accessing supports can be complicated, costly and time consuming. This experience extends across mainstream and foundational service systems, as well as for participants within the NDIS.

- The NDIS currently has multiple functions to help participants navigate in and outside the NDIS. However, these roles are split, and sometimes unintentionally duplicated. There are also issues with the implementation of the Partners in the Community program and support coordination is not available consistently or proportional to need.

- It is critical that there is support consistently available to help people with disability and families navigate the disjointed and complex government service systems. All people with disability should have access to a Navigator to help them find and coordinate the support they need and achieve what is important to them.

Recommendation 4: Support all people with disability to navigate mainstream, foundational and NDIS service systems

- Action 4.1: The National Disability Insurance Agency, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a local navigation function to help people with disability find supports in their community and make the best use of their funding.

- Action 4.2: The National Disability Insurance Agency, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a Specialist Navigation function for participants who have more complex or specific needs that cannot be reasonably met by general navigation support.

- Action 4.3: The National Disability Insurance Agency should ideally adopt a joint commissioning approach to deliver local navigation support within a nationally consistent framework developed in partnership with other relevant Australian government and state and territory government agencies.

- Action 4.4: The <u>National Disability Insurance Agency</u> should design, test and implement the navigation function gradually, prioritising continuity of support for participants and their families and a smooth transition for the workforce and market.

3.1. Service systems are complex and difficult to navigate

Most people with disability have multiple interactions with a range of government service systems and programs, including the NDIS, as part of their lives. For too many, navigating multiple disjointed and siloed service systems poses significant challenges in accessing the support they need.

The NDIS itself is a particularly complex service system to navigate. In response to this, a number of different roles have been established to assist participants and their families. The variability and overlap of these roles has resulted in fragmentation of supports. In parallel, there significant gaps also persist, which means support is not consistently available to all participants.

A new approach is necessary to deliver high-quality and consistently available support to assist people with disability and their families navigate NDIS, foundational, mainstream and community supports and services. This centres on the introduction of a local Navigator function to help all people with disability aged under 65 find supports in their community and make the best use of their funding. This should be coupled with a Specialist Navigator function for participants who have a higher level of needs. These reforms are essential to ensure people with disability do not miss out on support simply because service systems are disjointed, it is too difficult to find services and supports or too difficult to access them.

This must be underpinned by proposals for expanded foundational supports (see Recommendation 1) and more inclusive and accessible mainstream services (see Recommendation 2). These reforms must be considered as a package – outcomes for people with disability will not be improved if there are not sufficient high-quality, inclusive and accessible supports to connect people to.

Introduction of a Navigator function is also a key enabler of reforms proposed to the participant pathway (see Recommendation 3).

3.1.1. There are a myriad of different roles, functions and organisations involved in supporting people with disability to navigate different service systems

There are a wide range of different roles, functions and organisations currently involved in assisting people with disability to manage NDIS complexity and navigate different service systems. This is a combination of support that is available to all people with disability and some specific supports available only to particular participants based on their specific needs or circumstances. An overview of the roles and types of support is provided in Figure 46.

Figure 46: Summary of roles and supports currently available to participants

	Who is supported	What support is provided							
		Find other support	Info about NDIS	Support access request	Collect info for funding	Develop plan for funding	Decision about funding	Implement plan	Collect intel for govt.
Disability Gateway	All people with disability	✓	✓						
Early Childhood Partner	Participants <9 years	✓	✓	✓	✓	✓		✓	✓
Local Area Coordinator	Participants >9 years	✓	✓	✓	✓	✓		✓	✓
Remote Community Connector	People with disability in remote areas	✓	✓	✓	✓	✓		✓	
Support Coordinator	Funded participants	✓						✓	
Specialist Support Coordinators	Funded participants with higher needs	✓						✓	
Psychosocial Recovery Coach	Funded psychosocial disability participants	✓						✓	
Plan Manager	Participants who don't self-manage							✓	✓
NDIA Planners / delegates	All participants				✓	✓	✓		✓
NDIA contact centre	All people with disability		✓	✓	✓				✓

While well intentioned, the myriad of roles and organisations has added significant complexity to an already complex service landscape. It is often not clear who is responsible for what. Participants do not have a clear entry to navigation support, nor a single point of contact. While roles have been introduced to cut through the complexity of the NDIS, they have often added to it.

A lack of clear roles, responsibilities and expectations has also led to variable approaches and service quality. In practice, many staff and organisations provide much more than the functions presented in Figure 46. At the same time, many organisations offer less than is indicated. These variations and inconsistencies lead to gaps in some situations and overlaps in others. It is often not

clear which organisation delivers which support type across the different roles, particularly for participants who have multiple organisations supporting them.

3.1.2. There is very little navigation support available to all people with disability

People with disability have understandably struggled to navigate the complex service systems of mainstream, community and NDIS funded supports. A person with disability may interact with multiple programs or systems at any given time, including education, health, housing, justice, family or income support or employment. Each service is administered by a different department within a government and sometimes by a different level of government. The NDIS adds a new layer of 'disjointedness' and another complex system to navigate.

> *"The National Disability Insurance Scheme has disrupted integrated service provision. The NDIS creates an environment in which disjointed services are the norm."*
> *– Consultant Paediatrician* [654]

Getting help to find, arrange and connect with supports and services is challenging. People with disability and families carry a large administrative burden trying to understand and navigate these various programs and governments. Complex systems make that task unnecessarily difficult.

There is very little support available for people with disability who are not NDIS participants. Partners in the Community were originally intended to play a broad role supporting people with disability including providing:

- Information about what supports are available in mainstream service systems and the local community.
- Help to connect to the available supports.
- Support to build individual capacity and capacity of community services to be more inclusive and accessible for people with disability.
- Support to encourage growth of more inclusive and accessible community services.

However, Partners in the Community have had almost no capacity to fulfil these broader roles. Most of their capacity has been re-directed to support the transition to the NDIS, gathering information and building and reviewing plans. This has created an enormous gap in the navigation support that all people with disability were intended to receive through the initial design of a three-tiered framework of support.

> *"The NDIS application process really assumes that either the application is being done by abled parents for their child or by someone who has no cognitive issues, no brain fog, no mental exhaustion. If you're an adult who is applying without your parents shepherding, you through the process and you do have cognitive issues or brain fog or mental exhaustion the application process is just overwhelming and inaccessible. The local area coordinators who are supposed to shepherd you through the NDIS assume you have no cognitive issues, no brain fog, no mental exhaustion and if you*

do it's very, very challenging and in some cases I would say impossible." – Anonymous[655]

The National Disability Gateway was introduced as an alternate way to help people with disability find information, acting as a central referral point to disability information, supports and programs.[656] It had a vision of helping people with disability to navigate their own way to supports across multiple service systems. The reality fell short of this ambition.

The Gateway website includes long lists of potential information and services that may be available in a state or territory. It does not have the functionality required to identify local services that are available at a postcode or local government area level. The majority of the information appears only to link readers to external, third-party websites. It does not provide further information or guidance on matters such the eligibility criteria, suitability of a service to the reader's circumstances, service capability or quality.

"There's a disability gateway, which is just ridiculous to navigate. It's hobbled together like bits of information from just disparate places on the internet and it's just ridiculous or there's that list of service providers. That's like a million kind of pages long that's just impossible to even use and you don't even know how up to date it is." – Anonymous [657]

"There is extensive information online about services and activities open to people with disability, including dedicated resources and databases created and designed to help people with disability find services and support. However, details important to prospective service users - including costs, accessibility for particular needs, location, wait times, and eligibility for support or concessions - are missing, inaccurate or outdated in online databases and gateways. The time and effort involved in navigating and sifting the volume of information online can be overwhelming and frustrating." - Disability Advocacy Network Australia [658]

3.1.3. Navigation and coordination support for participants is primarily focused on access and planning activities and varies significantly in availability and quality

The NDIS is a complex system which requires participants and families to understand its boundaries, including where and how the scheme connects (or not) with other service systems, and to identify and coordinate supports to meet their needs and achieve their goals.

"Navigating the NDIS requires experience, education, strong communication skills and tenacity." – Provider [659]

The Productivity Commission originally envisaged Local Area Coordinators would have a key role as "the scheme's case managers".[660] They were expected to provide a "broad" range of support including "individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical

area".[661] The intention of case management for participants was that there would be significant support available to help navigate the NDIS.

However, the Partners in Community program has fallen far short of this vision. We have heard the same issues raised in previous reviews from participants, families and other experts. Issues raised fall broadly into two main categories.

Firstly, the Partners in the Community program has become almost exclusively focused on access and planning activities. There is a lack of meaningful resources and time dedicated to community development or people not eligible for individualised funding. This has contributed to the growing gulf between participants and non-participants.

Secondly, there are significant issues related to the availability and quality of Partners. Participants view Partners as agents of the NDIA. We have heard that availability and quality varies significantly and interactions have become transactional, rather than relational. High caseloads, high staff turnover, lack of consistency, lack of disability experience or understanding of diversity, and sometimes judgmental treatment of participants were all common sources of complaint.

> *"Experience with LACs varies widely, some are available, knowledgeable and helpful while others avoid contact, give incorrect advice and make the process very stressful."*
> *– Australian Federation of Disability Organisations* [662]

> *"We are not kept updated with changes to our LAC and often my children have different LACs which can be frustrating." – Participant* [663]

The limited ability of Partners in the Community to perform the full range of functions originally envisaged has resulted in many participants not getting enough support to help them decide how to best use the funding they receive through the NDIS. After a plan is provided, there is little follow up or support available to participants unless support coordination has been funded in their plan.

> *"Navigating the NDIS has become so challenging, that a lot of Participants/carers have given up because it's not worth the additional stress." – Carer* [664]

We have heard that one of the biggest challenges participants, families and supporters face is knowing where to find supports and which provider to choose. This can be particularly difficult for participants in regional and rural areas, where there may be a lack of support available, or for people with higher support needs who need to coordinate across a range of different providers.

Receiving any navigation-style support in the current system is largely dependent on a participant being funded for support coordination. Support coordination was a new function introduced with the roll out of the NDIS. Effective Support Coordinators can assist participants to understand their plan and make the best use of their budget, connect people to local supports and assist participants to build their own capacity over time. Not all participants receive funding for support coordination, and approval varies widely among participants, even when they have broadly similar circumstances, support needs and NDIS plans.

We have heard that decisions to include, vary the amounts, remove or terminate funding for support coordination seem arbitrary, unfair, inconsistent and not informed by evidence that is factored into other areas of a participant's plan. Decisions about funding can frequently be influenced by how well the participant and/or their support coordinator advocate for the funding.

> *"Support Coordination isn't just an option for Participants, it's a must have thing. Participants need an advocate on their side who knows the system, how to interact with providers and to book services. Not having this is wasting the NDIS's money, as participants who don't have these services are left spending their funding without guidance and are open to exploitation." – Participant* [665]

> *"I'm sorry, my support coordinators, they don't help me. They don't support me… my husband was able to get three times more than I was, and it was just… I was confused. It's like, Why? I'm advocating for both of us. Why are you getting more funding? And I'm really not getting anything… I've got a long list of reports. My husband has nothing and it feels like an injustice at the moment. He has a lot and I've got barely anything. I've got looking after our kids as well and our plans of exactly for one year each and the disparity is so different." – Anonymous* [666]

We received strong feedback from participants about the variability of quality of support coordination. We heard that some providers are highly valued by participants and their families. However, we also heard about other providers that do not provide support coordination with sufficient care, skill, independence or integrity. Some participants told us that their Support Coordinator has little understanding of their disability or their circumstances and failed to provide the support the participant required. There is little consistency across the support coordination market and participants demonstrably can experience a lottery of whether their provider or specific Support Coordinator is effective. Too many are not.

> *"I've gone through with a lot of people being assigned to support me that don't have any understanding of mental health… I've really learnt what support coordination isn't, rather than what it should be." – Participant* [667]

Support Coordinators told us that their effectiveness is constrained by the NDIS' pricing model, particularly when assisting participants with more complex and higher levels of need. Support coordinators are often expected to take on case management functions. This can include being a central contact point assumed to take on the responsibility for holding and maintaining essential personal information (e.g. medical, financial), and providing after hours service in a crisis (e.g. when an individual support worker calls in sick before an essential shift). The perception of participants, other services systems and even the NDIA at times, that support coordination is perpetually 'on call' creates an expectation gap between what participant may need or want from their Support Coordinator, and what can realistically be provided within the arbitrary time (hours of support) and fixed duration of funding allocated by the NDIA.

"Sometimes we get up to 18 phone calls a day from one participant with complex needs. There's no funding for that" – Provider [668]

The effectiveness of support coordination can also be impacted by perceived or real conflicts of interest. A real or perceived conflict of interest can exist where the support coordinator puts their own interests ahead of participants in supporting participants to choose other, direct supports and services. This risk is particularly high in situations where the same organisation (or corporate group) may be providing support coordination and delivering direct supports such as personal care, Supported Independent Living, community participation and other supports funded by the NDIS. Approximately 80% of providers who claimed intermediary supports during the quarter ending 30 June 2023 also delivered other NDIS supports.[669]

Support coordinators may be acting in their own interests rather than the participants' interests if they are encouraging a participant to continue to utilise supports delivered by their own organisation rather than supporting the participant to consider alternative approaches to service delivery. This is particularly problematic when the participant may not have informal supports or other people in their lives who are able to provide independent advice. The issue of client capture has been repeatedly raised by Disability Representative Organisations and advocates, particularly in recent years, but has remained unresolved. An alternate way is needed to remove this conflict of interest while maintaining high quality supports for participants.

Box 24: The NDIS Commission Own Motion Inquiry into Support Coordination

The NDIS Commission recently conducted an Own Motion Inquiry into Support Coordination and Plan Management. The Inquiry examined:

- **460 complaints about Support Coordinators** made to the Commission
- **40 complaints made by Support Coordinators** to the Commission raising concerns about a participant's other supports
- **Approximately 1,500 reportable incidents** involving support coordination notified to the Commission all since 2022.

There is currently little measurement of quality or participant outcomes in relation to support coordination.

The original design of support coordination anticipated that a participant's need for it would 'naturally' decrease over time. The initial expectation seems to have been that while supports were first established and new NDIS participants had gone through a period to better understand how to control and choose their NDIS supports and services, a navigator-type role had some value. After those early years, however, any need for system navigation was expected to diminish for most participants.

This was and remains a flawed assumption for the majority of participants given the significant complexity of the NDIS and regular changes to policies and rules. It also was an unrealistic

expectation given the limited opportunities for choice and control in disability service systems prior to the NDIS. It also failed to take into consideration the large numbers of people with a cognitive disability in the scheme who would require more support to navigate a new and complex scheme and genuinely express preference and choice.

> *"In our recent appeal I was asked "what further supports does your SC need to set up?"... I was actually speechless - there's a lot of work ahead. When there's such a gap between their understanding and your reality frankly you despair. I'm of the view that the NDIS would rather not have competent independent Support Coordinators as they keep workers accountable and act as a check and balance to the agency. Which of course is all the more reason to keep them. There's also a blanket policy that the first plan "is an establishment plan" then you progressively reduce SC in the belief the participant will self-coordinate..." – Carer* [670]

3.1.4. The approach to funding specialist support coordination for participants with higher and more complex needs is variable and confusing

Specialist Support Coordinators are currently funded to support participants with more complex support needs. It is typically funded as a time-limited support for participants with high levels of risk in their support environment, for example, interactions with the criminal justice system or complex behavioural support needs. Most participants currently with Specialist Support Coordinators are also in the Complex Support Needs pathway.[671]

There are many other participants with similarly complex circumstances, also interacting with other service systems, who are not in the Complex Supports Needs pathway but have funded hours of Level 2 Support Coordination, set at substantially higher levels than the average. This additional level of support is typically funded to address the significant and complex barriers to plan implementation, such as where there are multiple complex interfaces, or resolving crisis situations.

Specialist Support Coordinators are expected to bring a higher level of expertise and experience to manage this complexity. They are often but not necessarily allied health professionals.[672] Specialist Support Coordinators (Level 3) can charge prices ($190.54) that are almost equivalent to NDIS therapy prices ($193.99) and are almost double the price limit ($100.14) of Coordination of Supports (Level 2).[673]

This higher level of support is needed by some participants, but the variable way that it has been delivered has led to confusion. For many participants, families and providers, it is unclear why some participants have been approved for a Specialist Support Coordinator and others have not.[674] The connection that has been created between the entry to the NDIS Complex Support Needs pathway and Specialist Support Coordination lacks a nuanced understanding of the lives and support needs of some participants not on that pathway. The link adds more unnecessary complexity.

> *"There does not seem to be consistent criteria for Complex Support Needs pathway or for Complex Support Coordination... Support Coordination funding model opposes the interests of the service provider to those of the client. The low hourly rate paid for*

support coordination, and the inconsistency of funding specialist support coordination, makes service provision a marginally unviable business proposition." – Provider [675]

We have also heard there is confusion about the difference between Level 2 Coordination of Supports and Level 3 Specialist Support Coordination. Specialist Support Coordination is often funded alongside Level 2 Support Coordination, with the view that the Specialist Support Coordinator can address the immediate barriers with the other support coordination providing longer term support. While a Specialist Support Coordinator is expected to be "appropriately qualified and experienced practitioner to meet the individual needs of the participant's circumstances", there are no minimum qualifications or professional association requirements as there are for other therapy supports that have almost the same price cap (see price limits described above).[676] This makes it difficult to understand where Level 2 Coordination of Supports ends and Level 3 Specialist Support Coordination begins.

"The role is incredibly complex, yet it is only defined by less than a page of text in the pricing arrangements documents and NDIS Quality and Safeguards descriptions for level 2 Coordination of Support, and less than half of that for Level 3 Specialist Support Coordination." – Provider [677]

A further challenge with Specialist Support Coordination is that they are required to undertake quasi-case management activities and roles based on the higher needs of the participant. However, Specialist Support Coordinators are currently intended to be a time-limited support that helps to effectively overcome complex implementation challenges and longer-term implementation support is provided by a lower level of support coordination. This means participants who may benefit from a long-term approach to case management and more intensive support are no longer able to access that level of support once a crisis has been deemed to be resolved.

"There is currently the potential for specialist support coordination to assist participants to navigate complex systems and obtain the services required to maintain their health, wellbeing and community connections. This specialist support coordinator role, at times, resembles the role of a case manager, which the NDIS design has never incorporated." – Australian Public Advocates and Guardians [678]

There has also been a failure from the NDIA to actively steward the support coordination market. This is significant as support coordination is a service that has undergone massive growth to meet the needs of the NDIS. Existing case coordination and case management providers have had to undergo significant change, while new entrants have sprung up to meet demand. This is a market that required significant stewardship which has not materialised. The NDIA only completed its review of the support coordination model and released its *Improving Support Coordination for NDIS participants* paper in 2021.[679] While this review of the support coordination model attempted to provide greater clarity on the role of support coordinators, it has not been enough to address the confusion that still exists across the various intermediary roles in the scheme. It is unsurprising there has been so much variation in this rapidly expanding market.

3.1.5. There is a lack of local intelligence gathering and reporting

One of the barriers to finding supports is a lack of information. This is true both for participants needing to understand what is available and for governments making policy and funding decisions for mainstream and foundational services and as stewards of the NDIS market. Having limited information makes this much harder.

There is currently limited data for governments at all levels to understand gaps in supports for people with disability. These gaps may be due to a lack of availability or supports that are not inclusive for people with disability.

Although some local community organisations and advocacy services provide information on locally available services for some groups, there is no systematic approach to shed light on the current state of inclusive service provision for people with disability. Without a more systematic approach, policy and programs are not being informed by the realities of what is happening in local communities for people with disability. An effective policy maker requires high-quality intelligence and data about what is happening in communities.

This is despite improved data collection being previously recognised as a necessity for governments. The Australian Government made a commitment to "gain insights and put data in the hands of communities to help guide local decision-making and better direct funding" with additional funding of $31.4 million over 4 years from 2023–24 to meet the remaining costs of establishing the National Disability Data Asset (NDDA).[680] Once the NDDA is available, access to this intelligence will be a key enabler of the investment in foundational supports being effective and driving real change.

There is also a lack of accurate and timely data on where and why NDIS markets are failing to respond to the needs of people with disability. This has limited the ability of the NDIA, DSS and NDIS Commission to act as effective stewards of the NDIS market. See Chapter 4 for more detail on the approach to stewardship in the NDIS and issues with NDIS markets.

3.1.6. Proactive navigation support is needed for all people with disability

We propose that people with disability under the age of 65 and NDIS participants of all ages should have access to a local Navigator who acts as their agent. This will ensure there is high-quality support consistently available to help people with disability and their families find and access supports across mainstream, foundational service systems and the NDIS. People aged over 65 who are not NDIS participants should primarily access the aged care system. However, some of the information provided through general foundational supports would be relevant and available to them (see Chapter 1).

Overview of the new approach

Navigators will also provide more support to participants inside the NDIS. This will involve helping participants to connect to mainstream and community supports as well as to make the most of their NDIS funding.

Our proposed approach (Figure 47) includes a General Navigator available for all people with disability, with a Specialist Navigators for participants with higher levels of need. Dedicated expertise in areas such as housing and living and psychosocial disability would also be available.

Figure 47: Overview of the different navigators proposed

Navigation Support

Navigation Support

- Support available for people with disability.
- Helps to find and access local mainstream, foundational and NDIS services.
- Helps participants and nominees to develop a plan of action to implement mainstream, foundational and NDIS funded supports.
- Helping to identify supports and providers.

Strong local community connections and knowledge

Specialist Navigator

- Support for participants with higher support needs.
- Helps with similar activities to the General Navigator, with additional expertise and time to help respond to the participant's higher support needs, environmental complexity, or mitigate risk.
- Help with coordinating the range of services being accessed or needed by a participant.

Strong experience and qualifications working with more complex needs and circumstances

Additional Service Offerings

Housing and living

- Support for participants with housing and living needs.
- A type of General Navigator that supports the exploration of housing and living options.
- Support to participants and nominees to identify options, negotiate with providers, implement housing and living solutions and support trials of different housing and living options.

Strong understanding of best practice and innovative approaches to housing and living

Psychosocial recovery

- Support for participants with psychosocial disabilities who have higher support needs.
- A type of Specialist Navigator that supports a recovery-enabling relationship.
- Expertise in mental health to build capacity and capability of young people and adults to understand and navigate the NDIS, mainstream and foundational supports that work for them.

Strong experience and training in best practice approaches in mental health and working with more complex needs and circumstances

Navigation support should be delivered by skilled employees within organisations with genuine local connections, knowledge and links to local services. There is significant capability and expertise for many of the required activities in the new approach already in the market. This should be harnessed to help to provide continuity of support during the transition to the new approach.

The key functions of the general Navigator are set out in Figure 48. Further detail on each function is provided in the following sections.

Figure 48: Overview of the key functions of the Navigator
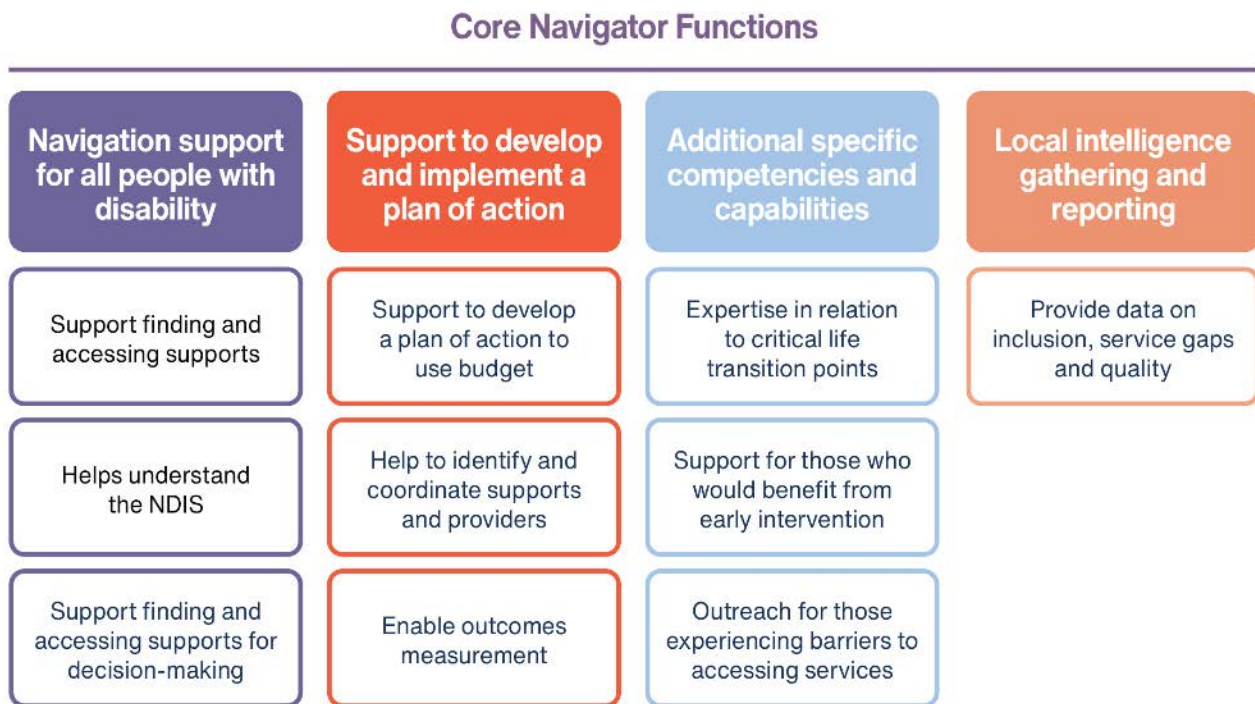
The local navigation function should be consistently available and provide a minimum level of support for people with disability. However, it must always be responsive and tailored to need.

This is particularly the case for participants who have higher levels of need. To ensure the level of support matches need, participants should be streamed into a specific level of support from a General Navigator or Specialist Navigator during the needs assessment (including an assessment of risk and safeguards in place). This should consider the individual's need and any risks.

The different levels of support should range from self-service for those who want and need only limited support from a General Navigator through to a much higher level of more specialised support from a Specialist Navigator. There should be different maximum caseloads established to align with this graduated approach to support. Figure 49 sets out potential levels of navigation supports, based on indicative caseloads and hours per month to demonstrate how the tailored model could work.

Figure 49: Overview of potential levels of navigation supports (hours are on average)
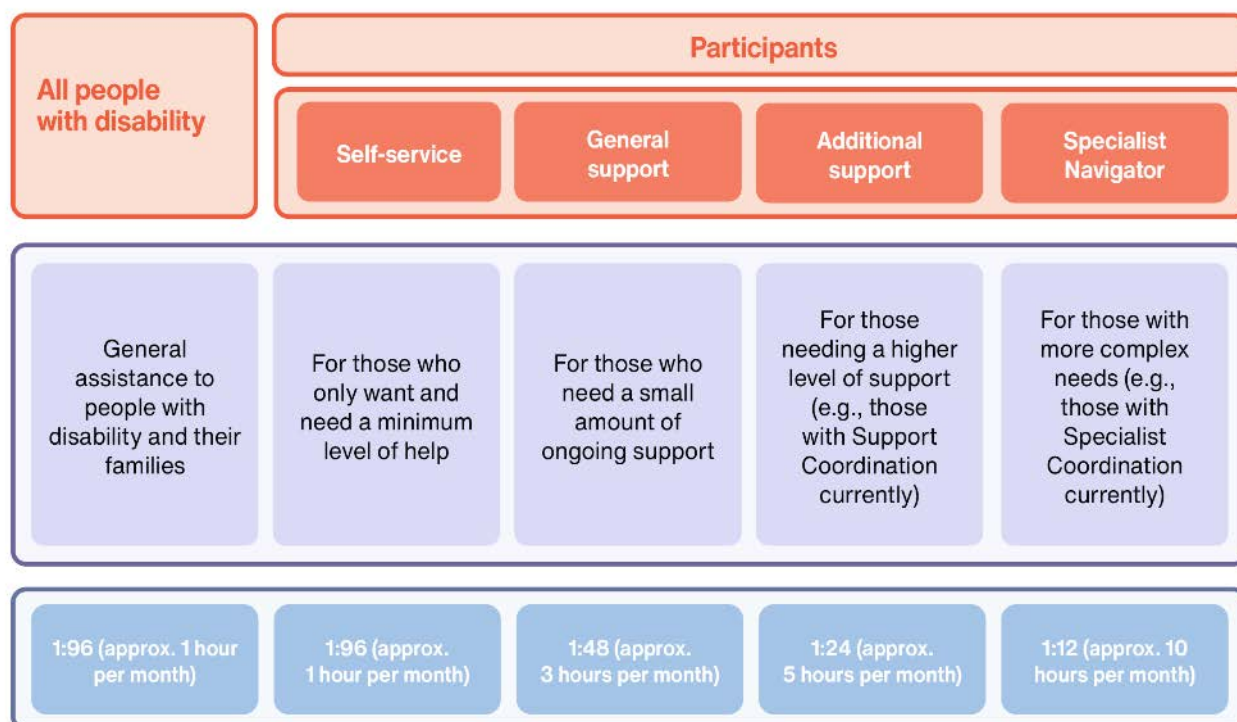
Navigation support for people with disability

A critical role of the Navigator must be to support people with disability to access more inclusive foundational supports and community and mainstream services, whether they are an NDIS participant or not. There are three key areas where Navigators can provide support for people with disability and their families; finding and accessing supports, help to understand and access the NDIS, and finding and accessing supports for decision-making.

Finding and accessing supports outside the NDIS

The Navigator should support people with disability to access mainstream and foundational supports available in their local area. Navigators must have a strong understanding of local contexts, including what is and is not available locally. This also means Navigators must be well connected with providers, local organisations and community and government services to be able to provide effective referral to appropriate services and supports. These may include disability specific supports, as well as community-based supports (e.g. local sporting groups, religious and cultural groups, arts and recreation).

Part of the success of the Navigator will depend on appropriate supports being available and accessible and inclusive. Without change, people will be 'navigated to nothing' or compelled to use services that do not meet their needs. Development of foundational supports (see Recommendation 1) and improvements to mainstream and community services inclusion and accessibility (see Recommendation 2) will be critical to the success of the Navigator in improving outcomes for people with disability.

Further detail on foundational services and mainstream and community supports is provided in Chapter 1.

Help to understand and access the NDIS

Navigators would also play a critical role in providing information about the NDIS. This includes helping people with disability and their families understand what the NDIS is, who it is for and how to make an access request.

There are some applicants who require tailored support to understand the requirements for an access request. The Navigator should provide this additional support so that would-be applicants do not miss out on needed support. Navigators should also help to connect applicants to mainstream and foundational supports while they are developing an access request or awaiting a decision. The design and implementation considerations set out below emphasise the need for the development of training in and accountability for culturally-safe and genuinely inclusive approaches to navigation.

Finding and accessing supports for decision-making

Navigators would have an important role in connecting people with disability to evidence-based opportunities funded through the foundational support system to support and develop their decision-making skills. These supports would be particularly targeted to people with a cognitive disability. Navigators should also assist family members and other informal decision-supporters to connect with training and information to better support them in their roles.

Navigators themselves must have an understanding and knowledge of supported decision-making as well as a demonstrated ability to embed supported-decision-making principles in their work with people with disability. Navigators should be responsible for ensuring participants are involved in the decisions about their supports where possible (even when nominees are in place).

Navigators should also play a key role in building capacity of all people with disability to make their own decisions.

Further detail on supported decision-making is provided in Section 4.

Support to develop and implement a plan of action for NDIS participants

There are three key areas where a Navigator could help participants:

- Developing a plan of action to use their reasonable and necessary budget
- Identifying and coordinating supports and providers
- Enabling outcomes measurement.

Support to develop a plan of action to use allocated funding

Once a participant has a reasonable and necessary budget approved, the Navigator should assist them to develop a plan of action to use their funding. The plan of action should set out how the participant would like to use their budget to meet their need and goals. The plan of action should be an iterative document that can be updated as needs or preferences change.

Navigation support should include providing information to participants about the types of supports that have led to good outcomes for other participants with similar needs, circumstances and goals. Navigators would have a role to give advice on choosing between different combinations of supports and different providers, including community and mainstream supports in their area. This support would assist participants and their families to be able to make better informed decisions about how best to be included in community, the supports they access, the providers that they utilise, and how to get the best value from their budget.

Once the plan of action is developed, the Navigator should provide support to implement it. Where it is difficult to access services the Navigator may help participants to pool their demand together to find and purchase supports (see Action 13.3). Pooling funding together can help overcome market gaps and get better outcomes for participants.

Help to identify and coordinate supports and providers

Navigators must have a good understanding of all relevant services available in their local area. This is to ensure that Navigators can assist participants, as required, to find providers and coordinate supports, whether they are funded supports or otherwise. This should happen as part of developing the initial plan of action, and during implementation of that plan of action.

The Navigator should conduct regular check-ins with participants to ensure they are satisfied with existing supports, if they have any issues with providers or workers, and whether there has been any change in circumstances. The Navigator should offer advice on alternatives where a participant's support needs are not being met or where there are other issues with services. Check-ins should include an update on the planned use of the participant's budget to check whether there are risks, including overspends or potential shortfalls.

The frequency of these check-ins would vary depending on whether the participant is self-servicing and what level of navigation support they have.

For participants who have an NDIS nominee, check-ins should include nominee's understanding of their role and how the nominee is supporting the participant in decision-making. Participants should be involved, as a matter of course, in meetings with Navigators unless that involvement is impossible. Participants should, where possible, have the opportunity to connect separately with the Navigator to discuss how their nominee arrangements are working.

Outcomes measurement and adapting approaches

As part of this work, the Navigator should work with participants, families and their supporters to understand and measure outcomes that matter to participants in ways that can be used to inform an evidence-base about effective (or ineffective) supports. This should include understanding the inclusivity and effectiveness of mainstream, local services, and disability funded supports.

Navigators and participants should agree on an appropriate intervals for an outcomes check-in, based on the length of their budget period, the nature of their goals, and other relevant circumstances.

The outcomes measurement process should be mapped to the most recent needs assessment, and form part of its design, so that de-identified data can help to continuously improve the budget setting process. Aggregated data should continue to be reported publicly through the NDIS Quarterly Reports.

Outcomes measurements should be used to inform Navigators' advice on supports and participants' decisions on how best to use their funding. It is critical that outcomes measurements are not linked to future budget decisions about individual participants. The achievement of desired goals is a complex, non-linear process that is influenced by many factors beyond funding for supports alone. There is currently a genuine and significant fear that revealing any positive progress will result in a future funding cut. Any reform to outcomes assessment must safeguard participants from such an unintended consequence (and the perception of it occurring).

The Navigator would also have an important role to play in amplifying the voice of participants in the services they receive where necessary. This may include assistance to change providers where one is not performing as required, helping participants to resolve issues, or holding providers accountable for better quality services.

Specific competencies and capabilities for Navigators

It is critical that navigation is delivered locally by people who have genuine local connections, knowledge and links to local services. This is to ensure they have a good understanding of the context of what is available locally for people with disability.

Navigators should have professional expertise and/or lived experience of disability wherever possible. People with disability and other relevant lived experiences must be prioritised for these roles. All Navigators should also be trained in trauma-informed practice, principles of supported decision-making and the provision of culturally safe supports.

There should also be specific expertise developed in key areas. These include: critical life transition points, early intervention and outreach for those experiencing barriers to accessing services (particularly the NDIS).

Expertise in relation to critical life transition points

The Navigator should be able to provide or link people to specialist advice to navigate key life transitions such as education, employment, and housing. Sometimes a Navigator will also be able to provide specialist advice themselves. In other circumstances, they may need to draw on the specialist expertise of other Navigators.

This could be delivered locally in some areas and may require more centralised support in other locations. Specialist expertise is unlikely to be available in every single location and may only be needed for a limited period for each individual. For these reasons local hubs must have links with expertise in other areas.

There should be expertise to assist with housing and living. This specialist support should provide advice when the person with disability and family is starting to explore housing and living options.

The purpose of this expertise is to provide time-limited support to the person with disability and their family to explore and understand housing and living options, identify and negotiate with providers, trial different options and assistance to implement housing and living supports during transitions. This support should not replace or duplicate existing support available from tenancy rights organisations or state and territory governments on housing. Further detail on housing and living navigation support is provided in Chapter 3.

Support for those who would benefit from early intervention

Participants who have accessed the NDIS through section 25 (early intervention requirements) of the NDIS Act are likely to need additional support and a differentiated approach from Navigators.

There should be additional support in the future provided by a strong general understanding of early intervention approaches across all Navigators. In addition, Navigators should have access to advice and support on appropriate best-practice approaches to early intervention, including for specific conditions expected to access early intervention. For example, this should include knowledge of best practice early intervention for adults with progressive neurological conditions.

In addition, there needs to be a strong baseline level of understanding of psychosocial disability and mental health for all Navigators. There should also be more specialist support for participants with psychosocial disability who also have high and complex needs. This should be provided by Specialist Navigators with experience and training in psychosocial disability and mental health. This is detailed further in the Specialist Navigator section below.

There should also be a specific approach for developing a plan of action and conducting targeted check-ins and outcomes evaluation for early intervention participants.

Navigators should deliver a differentiated approach to developing plans of action that are focused on the intervention expected to provide the greatest benefits and is ideally supported by evidence (wherever possible). There will need to be a strong link between the plan of action and the theory of change that was established on access to the NDIS (that early intervention supports funded by the NDIS would significantly improve outcomes and be cost effective for the participant).

The plan of action will need to be updated regularly and be supported by a tailored approach to targeted monitoring and outcomes evaluation, including:

- Navigators should conduct more frequent scheduled check-ins and use mechanisms such as case conferencing to discuss the individual's progress and advise the participant on the need for adjustments to the approach where expected benefits are not being achieved.
- Regular assessments of outcomes to determine if a participant continues to require and benefit from early intervention supports. These assessments should be shorter and more targeted than original needs assessments used for budget setting.
- Navigators should play a key role in providing insight into and evidence of need and success of interventions (or not). The purpose of outcomes assessments is to better understand what is working and what is not. This should help participants to change approaches, supports, or providers if interventions are not producing good outcomes.

Outreach for those experiencing barriers to accessing services

There should also be specific outreach for harder-to-reach groups who historically have been marginalised or excluded from access to mainstream and foundational supports or the NDIS. This includes people who are experiencing homelessness, people with psychosocial disability, First Nations and culturally and linguistically diverse people with disability. This should be part of the role of General Navigators.

Local intelligence gathering and reporting

Navigators should be a rich source of local data and intelligence about the inclusiveness, accessibility and availability of supports for people with disability, including data on unmet need. Navigators will be responsible for monitoring outcomes on access and inclusion in mainstream and foundational services, as well as identifying gaps in services in their local area. See Recommendation 13 for more detail on improved approaches to market monitoring and responses to challenges in coordinating the NDIS market.

This intelligence should be collected in a systematic way so that it can be reported back to government and provide feedback to policy makers to inform policy and program design. Disaggregated data must also be made publicly available to increase accountability for the availability of inclusive, effective supports.

This data reporting functionality should also be used to collate and report on the outcomes measurement activities being undertaken by the Navigator.

Extra support from Specialist Navigators for those with higher needs

Specialist Navigators should be available for participants with higher support needs. This includes participants who interact with other service systems, where significant risks have been identified, or where they have complex needs specifically related to their disability (disabilities). The need for a Specialist Navigator should be identified as part of the needs assessment (including an assessment of risk and natural safeguards).

Specialist Navigators would perform fundamentally the same functions as a General Navigator, but they would be delivered by staff with required expertise, appropriate training, experience and qualifications. This should include, but not be limited to, allied health professionals and social workers/youth workers. Typically, Specialist Navigators should have lower caseloads than General Navigators. This additional expertise, specified skill and time are necessary to respond more intensively to participants' higher support needs, environmental complexity, or to assist in mitigating risks to the participant.

Specialist Navigators should have responsibility for supporting a coordinated approach to the range of services used by a participant. They should also work to ensure services are maintained for participants with high behavioural support needs where it can often be difficult to find providers capable of sustaining appropriate supports. Some participants may access a Specialist Navigator for a specified period if their support needs increase, fluctuate or become unforeseeably more

complex. Other participants may require ongoing access to a Specialist Navigator. These variations will be determined through the needs assessment.

Psychosocial Recovery Navigators should be available for participants with psychosocial disability who also have high and complex needs. These Navigators will support participants with psychosocial disability who may need assistance to set and achieve goals, identify evidence-based supports, and connect with mental health, primary care and housing services. Psychosocial Recovery Navigators must have a strong understanding of evidence-based best practice approaches in mental health and supported decision-making. These Navigators should be required to meet, at least, the similar minimum experience and expertise requirements as Psychosocial Recovery Coaches. Importantly, this should be a needs-based support and not automatically allocated based on diagnosis. Further detail on psychosocial navigation support is provided in Section 6.1.2.

Designing the new approach

The NDIA should undertake a joint commissioning process with other relevant Australian, state and territory government agencies to establish the detailed design of the navigation function. This process must involve people with disability, families and sector representatives.

We have identified a set of principles to guide the commissioning process and the testing and scaling the navigation function.

Principles to guide the design and commissioning of Navigator functions

The way that the Navigator functions are designed and delivered will be crucial for success. The Review tested the idea of a Navigator through its participatory engagement process to develop an initial understanding of key success factors and important considerations for implementation of the functions.

Building on feedback from the participatory engagement process, we have developed the considerations in Box 25 to guide the NDIS Experience Design Office in its design of the Navigator function. The full set of considerations developed through the participatory engagement process are available in the *Co-Group Feedback to the NDIS Review Panel* (Appendix B).

> **Box 25: Navigation function design considerations**
>
> **Inclusive**
>
> What: The Navigator function must work for all people with disability, with a particular focus on designing an appropriate service for the majority of participants who have significant communication and support needs, as well as people with intersectional experience.
>
> How: The Navigator function must be designed with and to work for more complex participants first. In addition, the NDIA must work in partnership with culturally and linguistically diverse and First Nations people to ensure the Navigation approach is tailored to meet the needs of their communities.

Flexible

What: It is important that participants and families are able to choose the navigator and type of interactions with the navigator that works best for them. For example, navigation may be provided face to face, online, one to one, groups, phone, or peer navigation. If a participant is not satisfied with an individual Navigator, there should be a simple, clear mechanism for them to choose an alternative. This doesn't mean a participant who is not satisfied with a General Navigator could then choose a Specialist Navigator.

How: Minimum standards for choice and flexibility should form part of the design of the National Framework, outlined in more detail below. The needs assessment should allow participants, families and supporters to submit information on the approach to Navigation they would prefer. Participant preferences should only be set aside where there is clear evidence of a serious risk to the participant that can be better managed with additional navigation support. The level of support should be based on need. Navigation arrangements should then be reviewed on a regular basis, agreed with the participant and/or their family and supporters.

Sufficient Capacity

What: Navigators must have sufficient capacity to address each of the key functions that the Navigator is expected to deliver to ensure that the challenges with the current Partners in the Community model are not repeated.

How: Appropriate caseloads are essential, beginning with testing those indicated in Figure 49. There must be sufficient funding and clear performance indicators for the localised delivery of all Navigator functions, including ensuring capacity is reserved for local intelligence gathering and reporting.

Trusted and capable agents

What: Navigators need to be trusted by participants, families and carers, as well as the disability community more broadly.

How: Navigators must exclusively deliver navigation services within the NDIS. They must not ever be in a position where they may benefit from referring a participant to their own organization for NDIS services.

Training for Navigators should be designed with and led by representative organisations to ensure they have a trusted ability to deliver trauma-informed approaches, supported decision-making and to provide genuinely inclusive and culturally safe supports.

People with lived experience of disability should be prioritised for and supported in these roles, with public reporting on representation forming part of the national framework outlined below.

The joint commissioning approach must ensure that performance measurement and management incentivises Navigators to act as agents of the participant, not the NDIA.

The NDIA needs to take an approach to contract management that allows and encourages this to occur.

The design of the Navigator function should prioritise enabling Navigators to be a single point of contact for participants. This will require minimising turn over by creating roles that are attractive to staff, and prioritising continuity of care in delivery models.

Local delivery

What: The Navigator function must be delivered more locally than the current Partners in the Community program, with clear support and incentives for local consortia to deliver genuinely local approaches.

How: Footprints for organisations or consortia delivering the navigation functions should be smaller than the current 74 NDIS service areas. The commissioning approach should provide clear pathways for local consortia to deliver navigation tailored to the needs of a local community. A competitive procurement should test for and value demonstrated local connections highly.

Accountability for consistent, quality navigation support

What: The navigation function should be designed to deliver these localised models of navigation support within a nationally consistent framework. Clear accountability mechanisms are needed to ensure Navigators are providing a high level of service across Australia and that community concerns regarding quality are addressed promptly.

How: The design of the navigation function should be reviewed by the NDIS Review Implementation Advisory Committee (see Action 24.1), which will both include people with lived experience, and representatives from the disability sector.

The joint commissioning process should be first used to develop a national framework to provide guidance and accountability for the consistent delivery of localised navigation functions. The framework will set out the minimum service requirements and allow for localised service models that are tailored to individual community needs and achieve the target outcomes. Once the framework has been agreed, the joint commissioning process should be used to develop localised approaches to be tested and refined.

Outcomes and performance indicators, as well as a consistent approach to monitoring and evaluation, must be carefully designed with people with disability, representative organisations and people with frontline experience working in the NDIS. These must then be tested and adapted over time in partnership with participants and the organisations delivering the navigation function.

Navigators must be registered with the new National Disability Supports Quality and Safeguards Commission (see Chapter 5) to ensure appropriate safeguarding and avoid creating gaps in regulation.

Joint commissioning of Navigators

A key reason for dedicated navigation support is the complexity that people with disability and their families face having to access multiple service systems. This is in large part due to the multiple levels of government involved in the delivery and/or funding of programs that people with disability and their families interact with. The limited collaboration, coordination and integration between and within these levels of government and service systems means it is very challenging to navigate them.

A process of joint commissioning is essential to bring government together with people with disability, families and other sector representatives in the design and development of the navigation function. Importantly, joint commissioning will bring together the different levels, agencies and program areas across government. This should result in a more integrated approach across government and develop a more localised approach whereby state and territory governments can shape navigation models that work for local contexts and can be better integrated with local service systems.

Further consideration will need to be given to how Navigators operate in regional and remote areas where Partners in the Community have previously had limited or no presence and the support coordination, and psychosocial recovery coach market has been thin.

> **Box 26: Introduction to joint commissioning**
>
> Commissioning refers to a process to understand what is needed by the community or a particular group, identifying ways that the need may be met, and delivering an implementation approach to meet need. While it often includes a contracting stage, it is a more holistic process to identify and respond to need than simply procuring services from non-government organisations.
>
> Joint commissioning refers to the commissioning process being undertaken together by more than one government agency.
>
> This extends beyond simply collaborating, sharing information or engaging between agencies. It requires the agencies to work together throughout the commissioning process through an end-to-end partnership including shared accountability and decision-making. It should involve a joint commitment to the resourcing of the project to complete the commissioning work and funding of the resulting approach.

Testing and scaling Navigators

There should be extensive testing, trialling and refining of the navigation model with people with disability, families and carers, representative organisations and experienced providers of independent high-quality support coordination to ensure the future model will meet needs before system wide introduction. The focus should be on timely, graduated and coordinated transition to

implement the new framework of a successful Navigator model for the longer term. Ensuring continuity of navigation and direct supports for participants and their families must be a priority and will be essential to a smooth transition for the workforce and market.

Trials should be undertaken in multiple jurisdictions and locations, including different or varied approaches. Only after the trials have been evaluated and been found to provide good cost-effective benefits should new model(s) be prepared for scaling. The outcomes of trials should be known to all stakeholders and inform the approach to scaling new Navigator frameworks and service types. The design parameters will determine the pace and extent of change from current arrangements to the new future state.

Given the strong emphasis on local capabilities for Navigators, we anticipate that local organisations with a demonstrated connection to and understanding of local communities, and an understanding of mainstream, foundational and NDIS supports would be well placed to deliver navigation supports in the future.

This should include existing Support Coordinators, Specialist Support Coordinators and Psychosocial Recovery Coaches with demonstrated capability to deliver many of the proposed activities and provide continuity of support for participants. There is significant capability and expertise for many of the required activities of the new approach in the current market. This expertise, experience and capability should not be lost but harnessed as part of our recommended approach to navigation for the future. As the transition proceeds a high priority for the commissioning processes should be taking a systemic and strategic approach to identifying and eradicating current gaps in the market.

3.1.7.   Action & Implementation Details

Action 4.1: The National Disability Insurance Agency, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a local navigation function to help people with disability find supports in their community and make the best use of their funding

Significantly greater support should be provided by a Navigator with genuine local connections, knowledge and links to local services. Navigator support should be provided to people with disability, regardless of whether they are a participant or not. This should be aligned to the new Foundational Supports Strategy (see Action 1.2).

The Navigator should act on behalf and at the direction of the person with disability when providing information and supporting access to mainstream, foundational and NDIS services. This should include connecting people with disability to individualised safeguards, including support for decision-making. The Navigator should support participants to develop a plan of action, book and coordinate support where needed, undertake progress check-ins, and provide specific advice on key transition points or key issues. There should be additional

service offerings for those with psychosocial disability (see Action 7.1) and those with housing and living needs (see Action 8.2) as part of the Navigator function.

A carefully planned and staged transition to implement navigation would be essential to mitigate disruption to participants and their families. The staged approach to transitioning to the new approach should also provide the opportunity for existing Support Coordinators to transition to the provision of Navigator supports and allow continuity of support. Implementation should ensure the features of roles that are working well are retained and those that are not are reimagined (see Action 4.4).

Implementation detail:

- The NDIS Experience Design Office should design and test a dedicated set of navigation functions that are available to people with disability and participants. This would ensure the features of the current Partners in the Community and Support Coordinators that are working well are retained and those that are not, are reimagined. The Navigator functions should include:

    - Navigation support for all people with disability which includes:

        o Support finding NDIS and non-NDIS supports including mainstream, foundational supports and links to community services.

        o Help understanding what the NDIS is, who it is for and the process of making an access request if a person with disability is not already a participant. This includes outreach and information gathering for people experiencing unnecessary barriers to access.

        o Connect to individualised safeguards, including support for decision-making, capacity building and access to independent decision-support where required.

    - Support to develop and implement a plan of action, which includes:

        o Supporting participants and nominees to develop a plan of action to implement mainstream, foundational and funded supports in a way that is consistent with the objects and rules of the NDIS. This involves developing goals and working towards achieving what is important to participants. This also includes ensuring participants and nominees are aware of relevant evidence-informed supports and service delivery models.

        o Helping to identify potential supports and providers that may meet the needs of participants. This also includes helping participants have voice and/or to switch providers where the existing arrangements aren't working or a better alternative exists.

    - Intelligence gathering and reporting, which includes:

        o Providing data and intelligence on
            o demand for services and unmet need for all people with disability

- o gaps in local service systems
- o community inclusion and service quality
- o This data should be reported to all governments to incentivise policy responses to issues with inclusion, accessibility or availability of mainstream, foundational or NDIS services. Over time this data should also be made publicly available to increase transparency and help to incentivise providers to develop and innovate service delivery to address any gaps identified.

- Access to specific competencies and capabilities, including:

  - o Specific expertise in relation to critical life transition points (including education, employment and housing and living) to help navigate the complexity of the decisions and to build awareness and capacity with participants and nominees before reaching these critical periods. This should include specialist youth and young adult expertise to recognise the number of life transition points that occur during this time.
  - o Specific expertise to support people who would benefit from early intervention to access and adapt supports and combinations of supports that work for them (consistent with the intent of the early intervention pathway).
  - o Specific expertise in outreach for people with disability who may experience disproportionate barriers to accessing services.

- The NDIS Experience Design Office (see Action 24.3) should design the navigation approach with the following considerations:

  - Navigators should be funded outside of participant budgets.

  - The specific service model(s) and service requirements of the Navigator role should be established in a contractual agreement between the NDIA and Navigators.

  - Navigators should have clearly defined and transparent caseloads, as guidance:

    - o 1:96 (approx. 1 hour per month) for those who are effectively self-servicing.
    - o 1:48 (approx. 3 hours per month) for those who require a general level of support.
    - o 1:24 (approx. 5 hours per month) for those who require additional support, but not at the level of Specialist navigation (1:12 and approx. 10 hours per month).

  - Navigators must be registered with the new National Disability Supports Quality and Safeguards Commission to ensure appropriate safeguarding and workforce standards (see Action 17.1).

  - Design must involve people with disability who have complex needs including, people with an intellectual disability, people from First Nations communities, people from culturally linguistically diverse backgrounds and the sector and technical experts to ensure it captures the complex and intersecting needs of people with disability.

- Navigation must be delivered in a culturally safe and appropriate way by appropriately trained staff.

- Staff delivering navigation functions must have strong local knowledge, and the ability to deliver services in a trauma-informed way.

- People with disability expertise and lived experience of disability should be supported into Navigator roles wherever appropriate.

Action 4.2: The National Disability Insurance Agency, through the joint commissioning process described in Action 4.3, should be the lead commissioner of a Specialist Navigation function for participants who have more complex or specific needs that cannot be reasonably met by general navigation support

A Specialist Navigator should be available for participants with more complex support needs. This includes those with interactions with acute service systems and where complex situations or significant risks have been identified as part of the access or needs assessments. Opportunities for the National Disability Insurance Agency (NDIA) to jointly commission these specialist Navigators with other service systems should be explored by the NDIA to improve coordination.

Specialist navigation should be provided locally by staff with lower caseloads than other Navigators and have relevant experience managing complex situations and risks and ideally are qualified in allied health, social work or related fields. They should provide a higher level of support to participants when delivering Navigator functions to help respond to the participant's complex support needs, environmental complexity, or mitigate risk. Specialist Navigators should work closely with (but not duplicate) the role of NDIA Hospital or Justice Liaison Officers to ensure smooth transitions and coordination of supports for those participants who are exiting other service systems.

Implementation detail:

- The NDIS Experience Design Office should design and test a Specialist Navigator role to support participants with greater or more complex support needs, including those with psychosocial disability. This would ensure the features of the current Specialist Support Coordinators and Psychosocial Recovery Coaches that are working well are retained and those that are not, are reimagined. This role will deliver the functions of general navigation (see Action 4.1) combined with some additional supports, including:

  - Support to develop and implement a plan of action, which includes:

    o   Support to develop a plan of action to implement their funded supports. This needs to ensure there is a coordinated approach to the range of services being accessed or needed by a participant. In some cases this may require working with NDIA Justice and Health Liaison Officers to help people with complex needs transition in and out of other service systems and ensuring continuity of supports remain in place.

    o   Helping to identify potential supports and providers that may meet the needs of participants. This will include understanding and addressing the complex issues and barriers potentially impacting a participant's ability to access supports. It will also require working proactively to mitigate risk of service failure and responding to emerging issues with continuity of supports.

    o   Providing specialist expertise to navigate transition points in the context of complex situations and interaction of multiple services systems.

- Intelligence gathering and reporting, which includes:

    o   Providing data and intelligence on the availability and inclusivity (or otherwise) of mainstream services accessed by participants with complex needs (for example, specialist homeless services, young people exiting child protection).

- The NDIS Experience Design Office (see Action 24.3) should design the specialist navigation approach with the considerations described for general navigation function described above, along with the additional considerations:

    - Specialist Navigators will need to have significantly lower case-loads to enable them to provide targeted support. Expected to be approximately 1:12 and approx. 10 hours per month.

    - Specialist Navigators will have additional minimum qualification and experience requirements to ensure they have the necessary skills for this role.

    - Some participants may need specialist navigation on an ongoing basis and others might only need the additional support for shorter-periods of time before transitioning to a General Navigator.

    - Specialist Navigators will need to develop and have established networks with government and community services to be able to provide the support required for people with complex needs.

    - Specialist Navigators will need to be particularly skilled in supporting decision-making and having regular contact with the participants they are supporting as well as with others involved in providing support to the participant.

Action 4.3: The National Disability Insurance Agency should ideally adopt a joint commissioning approach to deliver local navigation support within a nationally consistent framework developed in partnership with other relevant Australian government and state and territory government agencies

Design of the navigation function should balance the need to design services that would be delivered locally to meet the specific needs of a community, while maintaining national consistency. This ideally should be approached through a process of joint commissioning between all Australian governments to ensure a coordinated approach to local service navigation. Local delivery should be underpinned by a nationally consistent approach to governance, branding, online service options, information management, communities of practice, monitoring and evaluation, and capability and training.

Wherever possible, there should be a local physical space or hub for people to interact with Navigators, co-located with existing community service organisations and foundational supports to increase service integration. The footprint for the navigation function should be significantly more local than the current NDIS service areas, and resourcing should allow for appropriate caseloads. This should ensure Navigators have the necessary local knowledge and connections, and can spend time providing genuine support. An alternative approach to delivering Navigators in remote communities should be considered to align with alternative commissioning of supports (see Action 14.1) and the general approach to outreach in the Navigator model.

Implementation detail:

- The NDIS Experience Design Office should use a joint commissioning approach to:

  - Develop a national framework to provide guidance and accountability for the consistent delivery of localised Navigation functions. The framework will set out the minimum service requirements and allow for localised service models that are tailored to individual community needs and achieve the target outcomes. The framework should include:

    o Governance approach for the Navigator function across governments, including an approach to resolving issues across governments and performing ongoing contract management consistent within a joint commissioning model.
    o Approach to delivering a single national online service option for navigation support.
    o Consistent branding to ensure the visibility of Navigators in local communities.
    o Information management and information sharing, including through communities of practice.
    o Ongoing monitoring and evaluation of the quality of navigation services.

- Basic and specialised training for Navigators that is designed and delivered with and by the disability sector, with a focus on approaches that work for people with the most complex communication and support needs.

- Design and deliver the Navigator and Specialist Navigator functions. This should take a place-based approach to navigation that incorporates physical and online spaces to deliver the functions described above in a way that meets the needs of the community. This should include co-location with new and existing foundational services, where integration benefits may be achieved.

- Develop an approach to design, test and implement the navigation function gradually that prioritises continuity of care for participants and their families and provides a smooth transition for the workforce and market (see Action 4.4).

Action 4.4: The National Disability Insurance Agency should design, test and implement the navigation function gradually, prioritising continuity of support for participants and their families and a smooth transition for the workforce and market.

The navigation function should be designed and tested with people with disability and other relevant experts through agile projects commissioned by the NDIS Experience Design Office (see Action 24.3). The design process should be aligned with the principles and implementation considerations set out in the *Co-Group Feedback to the NDIS Review Panel*, developed as part of the Review's participatory engagement process (for further details on the Co-Group's work see Appendix B). The design should include trial(s) across multiple service areas. Trials should encourage the formation of consortia and allow for multiple organisations (including existing independent support coordination providers) within a local area so that smaller organisations can contribute to genuinely local approaches. Trials should take an iterative and inclusive approach to designing functions with people with disability, as well as sector and technical experts. This should provide an opportunity to test both local approaches and measures to ensure national consistency and quality prior to wider implementation. The function should then be rolled out gradually to ensure continuity of support for existing participants, steward the significant existing capability in the support coordination and Partners in the Community workforce, and minimise impacts on the market.

Implementation detail:

- As part of the joint commissioning approach described in Action 4.3, the NDIS Experience Design Office should work with the other joint commissioners to develop detailed planning for the transition to Navigation and Specialist Navigation functions that prioritises continuity of care for participants and their families and provides a smooth transition for the workforce and market. This should include but not be limited to:

4. Support to empower people with disability to make decisions about their lives

- Participating in decision-making is a fundamental human right. The right to individual autonomy and to make one's own choices are enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and are core to the principle of choice and control in the *National Disability Insurance Scheme Act 2013* (NDIS Act).

- Without appropriate support, some people with disability cannot independently exercise this right. Many participants with cognitive disability and people with complex communication barriers have experienced limited opportunities to be involved in decisions, development or delivery of the support they receive.

- More must be done to support participants to exercise genuine choice and control and to be able to make decisions about their lives. The NDIA should embed a best practice, rights-based approach to supported decision-making. Participants, families, nominees and other decision-supporters should be provided with access to high quality information and training to support them in their roles as decision-supporters. Nominees should also be provided with better information, support and training about their role, with appropriate oversight in place.

Recommendation 5: Provide better support for people with disability to make decisions about their lives

📑 Legislative change required

- Action 5.1: The National Disability Insurance Agency should ensure participants receive accessible information and tailored advice to support informed decision-making.
- Action 5.2: The Department of Social Services and National Disability Insurance Agency should both ensure those with cognitive disability or complex communication support

needs are connected with capacity building support and other lifelong opportunities to build decision-making skills and experience.

- Action 5.3: The <u>National Disability Insurance Agency</u> should include an assessment of participants' need for independent decision-making support as part of budget setting and ensure participants can use their NDIS budgets to access independent decision-making supports.
- Action 5.4: The <u>Department of Social Services</u>, the new <u>National Disability Supports Quality and Safeguards Commission</u> and <u>National Disability Insurance Agency</u> should ensure decision-supporters have access to information, training and resources to assist them in providing best-practice support for decision-making.
- 🗐 Action 5.5: The <u>National Disability Insurance Agency</u> should reform the approach to appointing nominees, provide improved training and information to nominees, and increase oversight of nominee decisions.

4.1. Participants and families do not have access to the information they need to make decisions

Access to high-quality information and tailored advice is essential to informed choice. This is particularly the case in the NDIS, which is both a complex service system to navigate and requires complex decisions by participants, families and carers. However, we have heard repeatedly from participants about how difficult it is to access the information they need. A lack of access to tailored information and advice that is proportional to the complexity of the NDIS means many participants currently struggle to get the information they need to make informed decisions.

A new approach is required to ensure participants receive accessible information and tailored advice to support informed decision-making. This should prioritise helping people with disability access the information they need, in ways that are appropriate to their needs – whether that is specific accessibility, literacy, cultural, language or other requirements. Increased accessibility and availability of information is key to people with disability being empowered to make decisions.

While better information will help reduce some complexity for participants, it must also be underpinned by a commitment to reducing complexity in the scheme wherever possible.

4.1.1. The NDIS has increased the complexity of decision-making and participants do not have access to high quality information to make informed decisions

The NDIS was established on the assumption that participants and their families could navigate the system, advocate for their needs and make informed decisions about supports. However, the reality is that not all participants have the information, knowledge, networks, resources and confidence make decisions successfully.

We have heard that many factors contribute to this decision-making challenge, including difficulty accessing accurate information, discovering that information is often inaccessible, a lack of culturally appropriate information, and complexity of the NDIS.

Difficulty accessing information

Access to information to make decisions is a very challenging issue for participants and families. There are two parts to this problem, getting access to accurate information and the complexity of the information that is provided.

We heard that participants and their families find it difficult to access information they need about the NDIS. When they seek advice or further information from the NDIA, participants, Nominees and their agents often experience difficulty reaching someone who can assist them. There is no single point of contact available and enquiries often receive contradictory answers from different NDIA staff. There is frustration that the NDIS call centre, NDIS website and Partners in the Community do not always provide consistent or accurate information and advice.

> *"It can become time consuming and frustrating navigating the website looking for documents to use, how to guides, etc." – Participant* [681]

> *"Rarely do we get the same answer or support to a question… they don't know the answer… They lack CRM knowledge and are unsure where to look for something. I will need to make the exact enquiry serval times to get an informed answer." – Carer* [682]

> *"The information available to participants has not been clear and has not been conducive to decision making, including: Poor training of NDIA staff at all levels, resulting in inconsistent and unreliable advice being provided by contact centre staff, LACs, planners and other. Absence of information about appropriate terms and conditions applicable to service agreements, resulting in confusing, lengthy and unenforceable contracts terms. Insufficient (and contradictory) publicly available information about how funding can be used, and public claims of participant rorting and "crackdowns" resulting in participants being too afraid to make decisions and plan managers policing spending." - Villamanta Disability Rights Legal Service* [683]

> *"When I contact the NDIS and NDIA with issues and need support as a provider, I am always told I have contacted the wrong department and need to call a different number. When I call this number, I am again told the same thing and directed back to another phone number or email that cannot provide any help. There is no clear and consistent way to get clear and correct advice and support. Even via email requesting support I get no clear communication about the matter and my recent case for support was closed without any communication or explanation of this. It was only after I emailed back to request information on the progress that I was told the case had been closed and given again the 1800 NDIS number who again told me that they could not help me and to contact the NDIA. It feels like no one knows what their job actually is and how the agency and scheme operate. There is no consistency in advice from anyone." – Participant* [684]

Participants also told us that they struggle with the complexity of information they do receive. Language in correspondence and forms is difficult to interpret and understand. Participants often

report that staff from Partners in the Community and NDIA seem to lack awareness about the information needs of participants they are working with.

> *"I have recently received a letter from the NDIA stating that my sons plan will "continue with their current funding for a further 12 months" without any explanation nor a review of any sort. What does that mean I wonder... There is only the first name and initial of the person who sent the letter, along with the general enquires number and email to forward my questions to. The way the letter is worded is seemingly deliberately designed to be unable to be deciphered by those who have no inside knowledge of how the NDIA/S works. Perhaps the way in which the plans and letters are worded could be put into plainer and simpler language without the convoluted wording and ambiguity?" – Carer* [685]

> *"Investing in decent information provision within the Agency that's well-intentioned and aimed to have positive outcome for people, that's going to have a huge, positive impact." – Advocate* [686]

Accessibility of information

Participants have also reported receiving information in inaccessible formats. This includes people with vision impairments, intellectual disability and other cognitive disabilities not being provided with accessible information (such as in Easy Read formats). Planning and check-in meetings are seldom tailored to meet communication or accessibility requirements, and critical information discussed in the meetings is inaccessible.

These failures contribute to the exclusion of people with intellectual disability from being involved in planning meetings or decisions about their supports. Families often work hard to include the participant, but their efforts are not supported by the information provided by the NDIA and the format of planning or check-in meetings.

> *"I have a huge number of participants that have been actively excluded because they can't do video conference, and the Agency continually states that we've had feedback that video is more inclusive. Yes, it is for some people. I can't do supported decision making if I can't get the person I'm meant to be supporting into the room, and they're locking them out of the room by refusing to come into the room." – Advocate* [687]

> *"They should take time to know the person not just through the reports that are provided, but to really know the person and to do that. They've got to be an expert at ProloQuoToGo. Someone's got to be there to say, okay, you know, and also for my son to when he when he asked a question, not to defer him and say, Oh, look, we'll get to that later." – Anonymous* [688]

Information for First Nations people and culturally and linguistically diverse communities

First Nations people and culturally and linguistically diverse communities face additional challenges accessing appropriate information that enables them to understand and apply for the scheme.

"There is still higher amounts of misunderstanding and knowledge around the NDIS and evidence to support requests due to cultural and language differences" - National Ethnic Disability Alliance [689]

One of the themes identified by the NDIA engagement to co-design a new Cultural and Linguistic Diversity Strategy includes the need for "Accessible communications-disability concepts and NDIS communications should appropriately reflect cultural contexts to meet CALD participants' communication and language needs".[690] We also received submissions that highlighted communication barriers for culturally and linguistically diverse community members:

"Lack of information about the NDIS in Arabic language which is clear and easily understood... Problems with navigating NDIS website as in order to search for information in Arabic language you have to be able to read English to find the correct tab... Plans not being translated into Arabic language but rather sent to the NDIS participant in English." – Researcher [691]

Similarly, under the forthcoming First Nations Strategy, the NDIA has identified improved communication as a priority, including development of appropriate information and resources in language.[692]

"Low awareness and limited information about the NDIS can be a significant barrier. Many Aboriginal communities may not be adequately informed about the eligibility criteria, benefits, and available supports under the scheme. This can lead to a lack of understanding and reluctance to engage with the NDIS." – First Peoples Disability Network [693]

Moving beyond standard language translations, there continues to be a fundamental miscommunication between First Nations communities and the scheme. This is because disability services are underpinned by western norms, values and attitudes that inform how disability is perceived and responded to in processes such as assessments, supported decision-making or in communication materials.

Disability as a concept has little resonance for many First Nations people, and it can conflict with cultural identities and values, particularly that of inclusion. First Nations people often see what the current disability system defines as a profound or severe disability to be unremarkable, and simply representative of human diversity. For example, having a disability does not prevent or exclude First Nations people from having a valued role in community, responsibility to contribute, uphold and participating in cultural practices.

"Many Indigenous Australians view disability as a normal part of life, and may not identify as having disability, which can make it difficult to access NDIS services" - First People Disability Network [694]

Complexity of the NDIS

The challenge of accessing appropriate information is compounded by the complexity of the NDIS. Participants have described the many and varied challenges of navigating a complex system and having to make complex decisions within it.

Simply keeping up with the minimum administrative requirements of the NDIS requires a person to be able to organise reports to justify funding, navigate the NDIS portal, advocate for funding, engage with planners, and understand rules on what funding can be used for. NDIS systems also require participants and their representatives to negotiate with providers, sign service agreements and manage funding.

> *"Participants experience administrative pain points throughout this process: from gaining access (e.g. compiling paperwork, chasing the NDIA for a response), through to obtaining a plan, ensuring it meets their needs, and implementing that plan (when little support is given to help navigate markets and make decisions)." – Researchers* [695]

Participant choice and control over the planning and delivery of their supports is central to the NDIS. However, this requires participants to make many complex decisions. Prior to the advent of the NDIS, people were denied choices about the services they received. This means there are generations of people with disability and families who had almost no experience of making these sorts of complex decisions prior to the NDIS. Since then, they have had to quickly embark on a steep learning curve to more fully exercise their rights.

These structural barriers also applies to families with a child with disability or developmental delay, and some people with acquired disability. Many participants and families have never been required to navigate anything like the NDIS before. They have encountered immense challenges to get up to speed on the complexity of the NDIS very quickly. This has been exacerbated by NDIS systems that have often created additional barriers, not removed them.

> *"NDIS is a huge learning curve, it's been made too hard to understand how it all works. Surely it could be made easier to navigate the whole thing, you almost need a law degree to understand it all, that's one main reason I need the help from my support planner."- Person with disability* [696]

It is difficult to make decisions without information and advice that specifically relates to your circumstances or the parameters of the specific decision. We have heard that participants particularly struggle to understand what supports can or cannot be funded through their plan and how to determine if a support is sufficiently aligned to their goals and would be considered reasonable and necessary.

We have also heard that some self-managed participants struggle with the additional flexibility of their arrangements. They are fearful of doing the wrong thing with their funding in the absence of good guidance. While some observers often assume self-managing participants are the most capable decision-makers and require no additional support, this example highlights the criticality of providing information that is specific to the challenges facing a diversity of participants.

Many of the challenges we have heard about are linked to a lack of tailored information. This includes a lack of information about what supports are likely to achieve better outcomes, how to choose between different providers, and what factors to consider as part of making that choice.

> *"[It] requires significant time attempting to understand what services / skills / interventions my daughter may require, with no clear idea if they are likely to assist in addressing her specific issues." – Carer [697]*

The extent of the challenges inherent in navigating the NDIS is evidenced by the wide range of intermediaries (such as Partners in the Community and Support Coordinators) funded through the NDIS and the range of supports and information that have been developed (including peer-support groups, blogs, toolkits, cheat-sheets and other resources). However, these initiatives have not always been able to cut-through the underlying issue of avoidable complexity within the NDIS.

As discussed in Section 3.1.1, we have been told that having multiple intermediaries with different roles, responsibilities and availability adds to complexity within the system. There is unequal access to intermediaries, with some only available to particular groups. Additionally, participants often see Partners in the Community and some Community Connectors as not being on their side, as they are understood to be contracted agents of the NDIA. This can lead to an absence of confidence and trust.

4.1.2. All participants and families must have access to appropriate information and tailored advice

All participants must have access to information and tailored advice to support informed decision-making. Accurate and evidence-based information will help participants to exercise greater choice and control over their supports. This can be achieved by improved access to tailored information through the Navigator, Lead Practitioner for children under 9 years, and foundational support services.

Essential to this reform are commitments from the NDIA and new National Disability Supports Quality and Safeguards Commission to minimum standards of accessibility, reasonable adjustments for interactions with people with disability, improved access to culturally appropriate information, and broader improvements to reduce scheme complexity.

Access to accurate and evidence-based information

The proposed navigation function (see Section 3.1.6 and Recommendation 4) will have a critical role in addressing many of the challenges we outline above. Navigators should provide a principal point of contact and source of reliable information and advice. As agents of participants, Navigators would be responsible for providing tailored information and advice to assist participants to make decisions. Navigators should provide support in situations when decisions are particularly complex, such as when participants and families are learning about the NDIS, at key transition points, and when deciding how funding should be used and providers be chosen. Navigators would be expected to combine their knowledge of nationally consistent and accessible information with a strong understanding of local communities.

For families with younger children, the Lead Practitioner will play a critical role in providing evidence about best-practice early intervention supports (see Section 5.2.7 and Recommendation 6). The Navigator will also play a critical role in helping families to understand how to best utilise NDIS funding.

Proposed investments in foundational supports (see Recommendation 1) will also provide far more support for participants to access information. This will include access to information and resources, as well as connection to peer-support and self-advocacy which will support participants to get the information they need.

Accessible information

The NDIA must ensure its communications to people with disability reflect need and are provided in accessible formats. The approach should recognise that most participants in the NDIS have cognitive disabilities and/or complex communication support needs.[698] This means accessible information that works for people with cognitive disability should be the default.

The NDIA should work with representative organisations to identify how information can best be communicated in accessible formats. The NDIA should implement changes to their communications with the goal of being a leader in best practice accessible communication. This should be underpinned by a commitment to a minimum standard of information accessibility and being held to account when this commitment is not met. This should be a feature of the future Participant Service Guarantee.

At a minimum, people with intellectual disability should have access to Easy-Read information about applying for access, their NDIA funding and any plan of action to use funding developed with the Navigator. Some participants will require more tailored information which may be in the form of videos or other formats. This extends to Navigators ensuring participants have support to understand information provided by the NDIA or the Navigator.

Efforts by the NDIA should also extend beyond its written or video materials. The NDIA must ensure that meetings with its staff, assessors or other representatives are conducted in an accessible format and support the involvement of participants regardless of their disability. This includes ensuring the physical accessibility of the space in which meetings are held, as well as ensuring the format of meetings are tailored to the needs of all individuals. Progress against this objective should be measured, such as tracking the proportion of people with disability who are included in meeting (regardless of whether a nominee is in place). People with disability and families should be asked to provide feedback on the accessibility of the meeting. These measures should be publicly reported.

For reform to be successful, NDIA staff and representatives must have appropriate training on accessible communications, make meetings fully inclusive including options such as allotting more time, opportunities for breaks, and options for both virtual and in person attendance. Training should be developed and delivered in partnership with people with disability, their families and their representative organisations. NDIA staff should also have access to additional support and advice to inform their practice and continuously improve.

Access to culturally informed and responsive information

Commitments to accessible information must expand to include culturally responsive material that reflects the culturally diverse of all Australian communities. Communication needs to be culturally informed and responsive to be accessible for First Nations and culturally and linguistically diverse communities. This means, in addition to providing materials in language, the communication processes and materials must be adapted to reflect a culturally relevant representation of disability and care for the intended audience.

For First Nations people with disability, we believe there is a pressing need to recognise this core cultural difference through a significant and coordinated national effort to uplift the capability of the entire disability ecosystem and government services to ensure cultural safety for First Nations people with disability (see Action 2.10).

To achieve this goal for culturally and linguistically diverse people with disability, we have found that to improve communications efforts we must strengthen the ability of government to understand and respond to culturally diverse concepts of disability (see Action 2.2).

This reform work must be done in collaboration with these communities and their representative groups to ensure that information provided by all areas of the NDIA and the broader disability ecosystem meets community and personal needs.

Reducing complexity of the NDIS

In addition to addressing information gaps, it is essential that the complexity of the NDIS is addressed. The whole ecosystem, including the NDIS, must be designed to ensure that all people with disability can access information on no less favourable terms than other Australian. This means designing an inclusive information and access system that works for people with cognitive impairment as well as for anyone else. We propose a range of actions (Figure 50) that address the complexities hindering participants navigating the disability system.

In addition to implementing these actions, it is imperative that in the process of reforming the NDIS, no new additional complexity is unintentionally introduced. The NDIS Experience Design Office (see Action 24.3) should have a stated objective of reducing complexity so that all new policies, processes and procedures are evaluated for complexity, and their impact on the ease with which participants can navigate the system.

Addressing the complexity of the system will require a culture of proactively seeking out involvement by and feedback from participants and their families throughout the design and change process.

Figure 50: A specific aim of reducing complexity in the NDIS – an overview of the actions recommended by the Review to reduce complexity
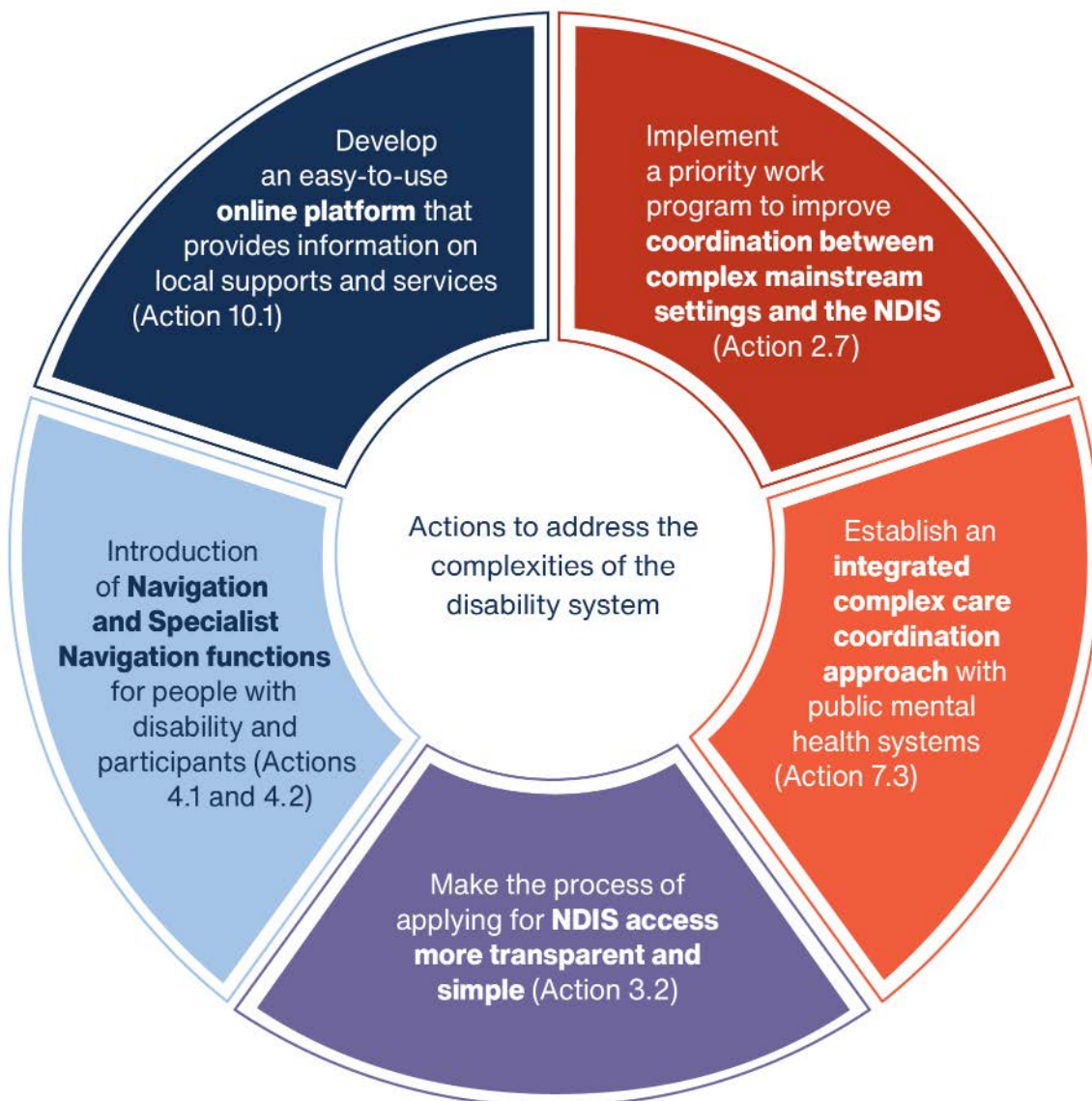
4.1.3.   Action & Implementation Details

Action 5.1: The National Disability Insurance Agency should ensure participants receive accessible information and tailored advice to support informed decision-making.

The Navigator should be responsible for ensuring participants receive accessible information and advice to inform decision-making, including connecting participants to other advice services. In addition, all communications from the National Disability Insurance Agency (NDIA) to participants and families must be provided in accessible formats aligned with participants' communication preferences. This should be supported by ensuring NDIA staff and Navigators have completed appropriate training on accessible communications. These

changes should occur in parallel to additional support for decision-making for participants with a cognitive disability or complex communication support needs (see Action 5.2).

Implementation detail:

- The National Disability Insurance Agency should ensure people with disability and their families have access to accessible information and tailored advice through the Navigator.
- The National Disability Insurance Agency should ensure that all communication with participants and their nominees is provided in accessible formats and responds to participant requests:

  - As part of this work, the NDIA should work with representative organisations to identify how information can best be communicated in accessible formats. This should consider new and different ways of communicating.

  - The NDIA should implement changes to their communications to address any issues which are raised through this work, with the goal of being a leader in best practice in accessible communication.

  - People with an intellectual disability should have access to Easy Read materials about their supports and budget as default. Additional accessible methods of providing information should be explored (e.g. video).

  - Meetings and interactions with participants should be conducted in an accessible format.

  - People from diverse communities should have access to communications in language that is culturally appropriate. Work must be done in collaboration with these communities and their representative groups to ensure that information provided by all areas of the NDIA and the broader disability ecosystem is meeting their needs

- The NDIS Experience Design Office (see Action 24.3) through the reform of the participant pathway should commit to and have a stated objective of reducing the complexity of the system.

  - This should involve actively seeking out feedback on issues and systems participants are finding complex and identify ways to address this feedback to reduce complexity. This feedback process should include participants with a range of different disabilities and life circumstances.

  - The NDIA should continue this as the reforms begin to be implemented.

4.2. People with cognitive disabilities have limited opportunities to develop decision-making skills

People with cognitive disabilities have historically had limited opportunities to participate in decisions about their lives and to practice and develop decision-making skills. This creates a cycle in which they continue to be excluded due to underdeveloped decision-making skills.

While much progress has been made, many people with cognitive disability still find themselves excluded from key decisions about their lives. Capacity building supports for decision-making are fragmented, with varying levels of access across different jurisdictions. Many of these supports are not appropriate for people with a higher levels of need or for those from diverse backgrounds.

People with cognitive disabilities in particular must be given more evidence-based opportunities to support and develop their decision-making skills. This will promote greater independence and self-direction and help to break the cycle of exclusion.

This should be underpinned by investments in foundational supports (see Recommendation 1) and the introduction of a navigation function (see Recommendation 4), which will also offer new ways to ensure that people with cognitive disabilities have equal opportunities and support to build their experience, skills and confidence.

4.2.1. People with cognitive disabilities have had limited opportunities to be involved in decisions and develop their decision-making skills.

The introduction of the NDIS was intended to increase opportunities for people with disability to exercise greater choice and more control over decisions about their supports. Despite this stated objective, there has been little investment and too few options to support NDIS participants to build their capacity and develop skills to make choice and control a meaningful reality. While this is true for all people with disability, it is a particular issue for people with cognitive disabilities.

Throughout the ten-year expansion of the NDIS, the scheme has become remote, complex, rules-bound and unresponsive. This complexity, combined with a lack of attention and investment in capacity building, has led to a cycle of exclusion, particularly for people with a cognitive disability. For many people with a cognitive disability the promise of greater choice and control in their lives is far from being realised.

Given that the scheme was anticipated to support large numbers of people with cognitive disability, it is particularly striking that it has failed to invest in capacity building or supports for decision-making at significant scale. The result is that the many benefits of greater choice and control have not been shared equally among participants. This must change.

A rights-based approach to ensuring participants have opportunities to make genuine decisions and develop their skills should underpin relationships within the NDIS. Capacity building supports to assist people to develop decision-making skills must be made available through foundational supports. The scheme must also ensure there is funding specifically available within whole-of-person budgets for participants who require additional support (see Section 4.3).

The NDIS should take a rights-based approach to ensuring participants have access to supported decision-making. This issue has previously been reviewed by the Australian Law Reform Commission who has recommended a principles approach to supported decision-making which can be applied to the NDIS (see Box 27). These principles have guided our considerations for how to address the need for decision support.

Box 27: A principle-based approach to Supported Decision Making[699]

In 2014, the Australian Law Reform Commission (ALRC) report, Equality, Capacity and Disability in Commonwealth Laws recommended all jurisdictions reform relevant laws and legal frameworks to formally recognise and promote supported decision-making in line with the following key principles:

- Principle 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- Principle 2: Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
- Principle 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
- Principle 4: Laws, legal frameworks and policies must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

Limited opportunities to participate in decision-making

People with disability face stigma, low expectations and negative community attitudes which impact their opportunities to participate in decisions about their lives.[700] Low expectations can mean families, support workers and others presume that people with disability, particularly people with a cognitive disability, lack the ability to participate in important decisions. Many people with cognitive disabilities and complex communication support needs have experienced a lifetime of being denied the right to make their own decisions or have control over their lives.[701]

In addition, decisions about children and adolescents are often framed as being made in their best interests, rather than involving the person in decision-making. This can limit their opportunities to develop and practice decision-making skills and navigate risk.[702]

Families of children with disability are not encouraged to take the same approach as children without disability who typically receive support for decision-making early in their lives and are gradually given more responsibility and exposure to risk as they age. In contrast, families of children with disability are often unsure how to involve their children in decisions that impact their lives. This is partly because they are not provided with sufficient information, advice or support.

This leads to adolescents with disability being provided far fewer opportunities to practice independence, experience autonomy, and engage in risk-taking behaviour when compared with peers without disability.[703] Outcomes data for adolescent and young adult participants (aged 15 to 24) reveals that most are not involved in making decisions regularly and want more choice and control in their lives (Figure 51).

Figure 51: Experience of choice and control amongst adolescent and young adult participants (aged 15 to 24) who have been in the scheme for four or more years as at 30 June 2021[704]
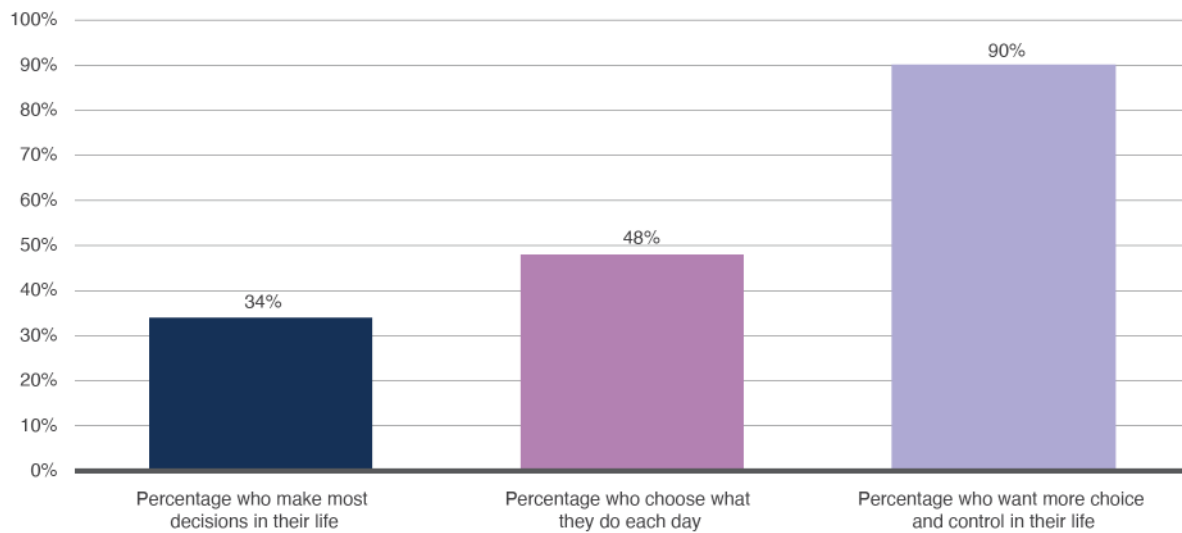
Adults with cognitive disabilities experience a similar lack of opportunities to be involved in making decisions about their lives. Decisions can often be made for people with disability with limited or no consideration of their preferences. This can happen for big decisions, such as where to live, or smaller decision, such as how to spend time during the day.

The level of access people with intellectual disability have to inclusive work and living settings has a strong, negative impact on their self-determination. Congregate settings tend to provide limited opportunities for people with disability to exercise genuine choice and control. People with disability within congregate settings are often not provided with information, education or skills to be able to input into decisions even at a group-level. They are also rewarded for compliance with decisions of providers.[705]

Less than half of adult (aged 25 and over) participants with a primary intellectual disability (including Down syndrome) report that they choose what they do each day (Figure 52). This is significantly lower than the 75 per cent of participants with other primary disabilities who choose what they do each day.

Figure 52: Proportion of participants aged 25 and over who choose what they do each day[706]

Chart showing two bars: "Primary intellectual disability (Intellectual Disability or Down Syndrome)" at 48% and "Other primary disabilities" at 75%.
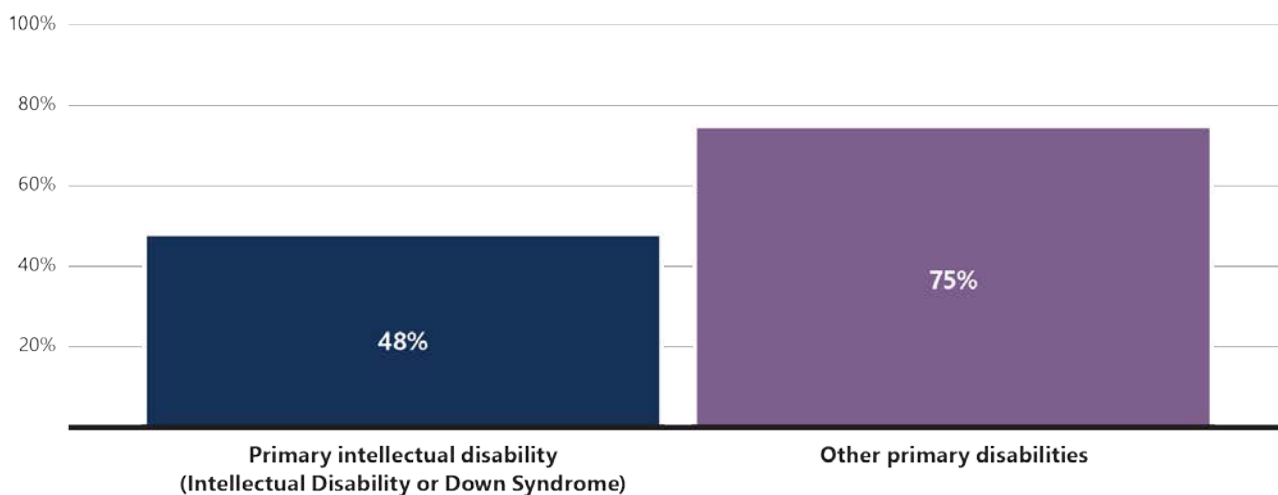
Supports to build decision-making capacity

There is currently no strategic approach to delivering and coordinating supports for people with cognitive disabilities to develop their decision-making skills.

We have heard from both advocates and families about the importance of having access to funded peer support and self-advocacy initiatives.[707] These types of programs help people with intellectual disability to build their skills and experience and provide important community connections. This theme emerged from policy workshops run on behalf of the Review by Inclusion Australia with advocates, researchers, family members and other experts.[708]

> *"The importance of peer support and self-advocacy was raised across the workshops. For people with an intellectual disability, this is fundamental to support positive life outcomes and community inclusion as well as enabling people to be active and empowered consumers in the NDIS market. Stable and sustained funding for the development and maintenance of self-advocacy and peer support groups and ecosystems across Australia is essential. This has been a marked gap in the NDIS environment to date." – Inclusion Australia [709]*

The Information, Linkages and Capacity Building Program (ILC) has funded a range of initiatives including high-quality resources, decision-support training programs and a range of self-advocacy programs. Unfortunately, due to the nature of the ILC funding, most of these initiatives are time-limited pilots and have unequal availability across jurisdictions.

Similarly, there have been projects funded through the NDIS Quality and Safeguards Commission, such as the recently released Deciding with Support toolkit, which provide resources on supported decision-making for everyone involved in behaviour support.[710]

Case Study 9: Deciding with Support Project

'Deciding with Support' is a toolkit of co-designed resources on supported decision-making for people involved in behaviour support.

The project was completed for the NDIS Quality and Safeguards Commission as a collaboration between Flinders University, the Council for Intellectual Disability and UNSW Sydney.

This toolkit includes Easy-Read resources for people with disability about supported-decision-making, and behaviour support plans.

It also provides specialised information for supporters, behaviour support practitioners, and providers including access to additional training on supported decision-making and rights.

Some participants have been able to access self-advocacy groups and training, but others have had little or no support. Grassroots self-advocacy groups have played an important role in the development of leadership skills, decision-making capacity, and community connections for people with cognitive disabilities and complex support needs. The absence of ongoing funding, resourcing and coordination available to support these groups has meant that many miss out.

The recently released NDIA Supported Decision Making Policy recognises the importance of capacity building.[711] However, it does not provide a clear approach to connecting participants with capacity building opportunities. The policy suggests that capacity building support for decision-making could be included as part of a plan if it were deemed reasonable and necessary. The policy's implementation plan includes an output to "develop processes to ensure NDIS partners are well connected with capacity building supports,"[712] but does not go to addressing the fragmentation of available supports. Feedback from participants and advocates suggests that further work is required to ensure the intent of the policy is realised in practice and that people are genuinely connected with appropriate support.

> *"We continue to see people with an intellectual disability left out of their own planning process while the NDIA speaks to providers instead. We have seen no evidence of capacity building for these clients (especially in group settings) to understand the NDIS process, what funding they have, and what decisions they can make." – Villiamanta Disability Rights Legal Service [713]*

> *"The provision of decision-making supports to people with disability has been slow to roll out. Measures for people with disability and their supporters to increase their own skills in decision-making are yet to be implemented in any widely publicised and generally known way." – People with Disability Australia [714]*

4.2.2.   People with disability must be afforded greater opportunities to gain experience and skills to make decisions about their lives

People with disability have the right to make decisions about their lives. Investment in decision-making capacity will lead to significant positive impacts in people's lives and their ability to be

more independent. Participants should have opportunities to be more involved in decisions about their everyday lives, as well as to make informed decisions about NDIS supports.

We are proposing a life-long approach to connecting people with cognitive disabilities to opportunities to participate in decision-making and build their decision-making skills and confidence. The proposed approach will also better support people with disability to build informal networks which can assist in supporting decisions and provide important social and community connections.

Ensuring people with disability have opportunities to participate in decision-making

As described above, people with cognitive disabilities often experience life-long limitations in access to decision-making. The NDIS must work to break this cycle of disempowerment. This should be addressed in different ways depending on the age of the participant and their needs.

For young children under the age of 9 and their families, Lead Practitioners (see Recommendation 6) will play a significant role alongside Navigators (see Recommendation 4) in linking families to appropriate mainstream and foundational supports.

This should include resources and information about independence and decision-support as well as to family peer support where families can learn together and develop skills. Families will be supported to embed early opportunities for inclusion, independence and participation in decision-making in their children's lives. This will help to ensure that children with cognitive disabilities have early experiences in making decisions about their lives and managing risks. Families will be encouraged to support age-appropriate involvement in decisions with gradual increases to independence and exposure to risk.

For older children, adolescents and adults, Navigators (see Recommendation 4) will work with the person with disability and their families to help them understand their rights and to identify what supports they need to more fully participate in decisions. Navigators should support participants to access the level of support they require to be more involved in decision-making, including as their needs fluctuate over time. These supports could include, but not be limited to:

- As a foundational support:
  - Peer-support networks
  - Self-advocacy groups
  - Tailored training
- As part of a needs assessment and reasonable and necessary budget:
  - Assistance to explore, set up and maintain networks of supports
  - Independent decision-support.

The Navigator must also be responsive to changing needs in playing this role. For example, some participants may initially want to join self-advocacy groups to develop their confidence. As they

develop their skills they may benefit from training-programs or workshops to further developing their skills.

> *"People with intellectual disability need to be supported to understand their rights... This is particularly important for participants who may be very reliant on one provider such as in SDA or ADEs. This support needs to be accompanied by understanding the right to take risks, make mistakes and learn from them (dignity of risk)." – Down Syndrome Australia* [715]

The Navigator would also need to work collaboratively with families to ensure all participants are involved in decision-making about their budget and supports. Wherever possible, the participant should be included in all discussions about their budget and supports, even when there is a formal nominee in place. This will require the Navigator to provide sufficient time and preparation for participants to be involved in these conversations and facilitate the discussion to support inclusion.

When nominee arrangements are in place, participants should be encouraged to express their preferences and views. This can also work as a safeguard to ensure that nominee arrangements are appropriate.

For these actions to be successful, the NDIA needs to ensure that its staff, assessors, and contractors receive training on supported decision-making. Each position must be provided with a clear understanding of their role in supporting people with disability and families to access the supports and resources they require. This training should be designed with and co-facilitated by people with cognitive disabilities. Awareness of supported decision-making and skills in best practices should be included as a Key Performance Indicator for all NDIA staff.

Opportunities to build capacity for decision-making

For the proposed approach to be successful, people with cognitive disabilities need to be able to access high-quality opportunities to build their confidence and skills in decision-making. The expanded approach to foundational supports (see Action 1.1) should support improved planning and coordination of foundational supports across jurisdictions. .

The development of new foundational supports for decision-making capacity must be disability-led, and facilitated by people who have decision-support needs. It is essential to build on high-quality programs that have already been developed across various government funding streams. A consistent and clear approach to outcome measurement should be embedded to ensure any investment leads to meaningful outcomes.

> *"People with intellectual disability recommend that other people with intellectual disability have access to workshops and resources that allow them to build upon their decision-making capacity and provide information that assists them to make decisions. They emphasised the importance of having opportunities to learn and practice decision making, and that this learning should start at school." – South Australian Council on Intellectual Disability* [716]

Investments in capacity building supports for decision-making must include:

A disability-led central mechanism to support and develop a best-practice approach to self-advocacy and lead collaboration across jurisdictions. This central coordination function should also have responsibility for identifying gaps in capacity building opportunities and jurisdictional inequities. This centralised approach would support organisations to develop high-quality, disability-led self-advocacy offerings and enable a centralised point of access for Navigators.

Disability-led organisations to deliver supported-decision-making training to people with cognitive disabilities and/or complex communication support needs. This training should be evidence-based and build on previous resources and materials that have already been developed through ILC and other government funded programs.

Disability-led self-advocacy networks and peer-support groups, with a particular focus on supporting decision-making capacity. These programs should be designed to provide support and opportunities to people with disability who require support for decision-making including participants with profound cognitive disabilities or complex communication support needs. This should be multi-year program funding to avoid the current gaps when projects conclude.

Capacity building opportunities should also be tailored to meet the range of needs and circumstances of people with cognitive disabilities. For example, people with complex communication support needs will require specialised opportunities to develop their communication and decision-making, including through the use of alternative communication strategies. Participants who have limited informal supports will require greater assistance in accessing and participating in self-advocacy groups and training.

> *"[The participant] just has you know, repeats a lot and can say yes or no, for many different reasons. Also, we use another method of you know, do you want, you know, Red, Yellow or something else, you know, that can that can be used for some things... it's done in all sorts of different ways. But when you're saying who, it's myself and making the big things, sometimes we use social stories, lots of visuals as well... He always needs the support to assist him in making his own decisions. So if some stranger come out and said, "Hey, mate, do you want to do this or that or whatever?" - he wouldn't be able to verbalize it, so he needs that support to support him in making a decision or to even get the answer out of what he wants to say." – Carer [717]*

A partnership approach should be utilised to develop capacity building programs that will meet the cultural needs of First Nations people and those from cultural and linguistically diverse backgrounds. This should include working directly with communities about preferred supports. Working in partnership with communities to develop appropriate supports is essential to meeting the culturally informed needs of participants.

4.2.3.   Action & Implementation Details

Action 5.2: The <u>Department of Social Services</u> and <u>National Disability Insurance Agency</u> should both ensure those with cognitive disability or complex communication support needs are connected with capacity building support and other lifelong opportunities to build decision-making skills and experience

The foundational support system should include funding for programs and initiatives that help to build decision-making capacity and independence for participants with a cognitive disability or complex communication support needs. At a minimum, this should include self-advocacy, peer-support, and training. It should include a disability led mechanism to support a coordinated approach to self-advocacy networks and peer support, as well as training on supported decision-making delivered by disability organisations. Within the NDIS, there should be support for participants to build networks to assist in support for decision-making (such as circles of support and Microboards) as well as informal networks to aid decision-making and increase social connections.

Implementation detail:

- The National Disability Insurance Agency, through its joint commissioning of the Navigator function (see Recommendation 4), should work collaboratively with families to ensure all participants are involved in decision-making about their budget and supports. Wherever possible, the participant should be included in all discussions about their budget and supports, even when there is a formal nominee in place.

- The National Disability Insurance Agency through the Navigator function (see Recommendation 4) must link all participants who require support for decision-making to Capacity Building Foundational Supports (see Action 1.3.4) which will provide opportunities to develop decision-making capacity and independence. This should include:

  - Access to self-advocacy networks and peer support which have been shown to support decision-making capacity.

  - Workshops and training to support decision-making skills.

- The National Disability Insurance Agency should ensure that all NDIA Staff, Needs Assessors, Lead Practitioners and Navigators have regular high-quality training on supported decision-making. Each position must be provided with a clear understanding of their role in supporting people with disability and families to access supports and resources.

- Australian governments through capacity building foundational supports (see Action 1.1) should:

  - Establish a disability-led central mechanism to support and develop a best-practice approach to self-advocacy offerings across all jurisdictions and to connect Navigators

to self-advocacy offerings. This central coordination function should include development of a community of practice, a robust measurement and outcome framework, and supporting collaboration and capacity building.

- Provide funding for local disability-led self-advocacy networks and peer support which include a focus on supporting decision-making capacity. These programs should be designed to ensure participants with more profound cognitive disabilities or complex communication support needs have opportunities to participate in peer-support initiatives.

- Make supported decision-making training available to people with cognitive disabilities and/or complex communication support needs. This should be delivered by disability-led organisations.

4.3. Participants are not getting access to the funded support they need for decision-making

In addition to support to build decision-making skills, there are also participants with higher levels of need for support for decision-making. Some participants have limited informal support for decision-making and are reliant on providers or other paid supporters to assist them in decision-making.

However, under the current system, the need for decision-making supports is not currently considered as part of planning meetings or decisions about funding. This means participants who may require decision-making support are not being identified or funded and are therefore unable to access the formal support they need.

To address this gap, participants should be assessed for their decision-making support needs as part of the needs assessment, and their whole-of-person budget allocation should reflect those support needs. This would ensure participants have access to independent support for decision-making to be able to navigate the NDIS and make informed decisions about supports.

4.3.1. Participants struggle to get the support they need for decision-making

Access to support for decision-making is needed for the vast majority of participants. Yet many participants do not have this. Consideration of the need for decision supports is rarely included in the development of NDIS plans.

Often there is a presumption that either parents or other informal supports will make decisions on behalf of the person or that providers will assist in coordinating supports for people with cognitive disabilities. These issues are particularly challenging for participants with no informal supports, those with ageing parents, and those from diverse backgrounds.

Decision support needs are not adequately considered in planning meetings

The majority of participants in the scheme have a cognitive disability and would benefit for support for decision-making. Despite this, there is no specific consideration of decision support needs within the planning meetings, unless it is raised by a participant, nominee or family. Decision support is also not included as something for participants to consider in the "Creating your NDIS Plan" booklet which supports participants to consider their goals and what supports they need in advance of attending a planning meeting.[718]

For participants with informal supports in place, there is significant pressure on family members to take on or continue in the role of supporting decision-making. A recent national survey of carers found that 83 per cent of family carers of a person with disability are providing support for decision-making.[719] In some cases, this works well for both the participant and family. For others, this can put significant pressure on family, or lead to a situation where families are making decisions on behalf of the person and trying to decide what is in their best. Often even when it is working, parents worry about what will happen when they are no longer able to provide support. There is little consideration by the planner of what supports might be needed to continue informal supports, or whether participants should be linked to more formal supports.

> *"We are our daughter's only reliable informal supports and it takes both of us as a team to give her the basics - let alone support her to pursue her life goals. If one of us becomes unable to go on, all of her informal supports collapse. We have two other daughters and five grandchildren. We are regularly left feeling that we neglect them (and ourselves) due to our caring roles." – Carer [720]*

> *"The choice to provide or receive informal care should sit with the individuals within the care relationship and that there should be no expectation that any individual should be required to provide or receive care from someone else simply because they have a pre-existing relationship." - Carers NSW [721]*

In addition, when parents of the person with disability are ageing or have changes in their health, this reliance on family for decision support can become particularly problematic.

> *"My husband and I are ageing and have our own health problems and cannot continue to provide support to our two sons who are participants of the NDIS and we are concerned about the future and whether they will continue to receive the support they need when we are no longer able to advocate for them." – Carer [722]*

Consideration of decision-making support needs is particularly critical for people with cognitive disability who have little or no informal supports. They are often reliant on providers or Support Coordinators to assist them in making decisions. These individuals can have inherent conflicts of interest to act as decision-supporters. Planning meetings for these participants rarely include consideration of any independent support for decision-making. Instead, the focus is on funding the direct supports for the participant.

Box 28: Previous work and recommendations on this issue

In 2023, the NDIA released a Support for Decision Making Policy and Implementation Plan, which utilises the ALRC principles outlined in Box 27.[723]

This policy recognises the importance of support for decision-making, and embeds changes to NDIA policy and procedures to promote the use of supported decision-making. The policy outlines that decision-making support can be provided as a general support or a reasonable and necessary (capacity building) support.

However, is not clear how this is being implemented. Participants and families have reported not being successful in seeking funding for decision supports.

The Australian Government also funded a National Disability Advocacy Program Decision Support Pilot to provide decision support for people who had limited or no informal supports and required assistance with decision-making. This commenced in 2019, was extended until 2023 and then ceased. This program was targeted at people with disabilities who have few or no family or friends in their lives and who need help accessing the NDIS.

An evaluation of this program was undertaken but has not yet been released. Advocacy organisations have expressed concern that after this program was ceased there was no clear place for people to go who did not have access to informal decision support.

> *"We have just had our funding after five years removed for that service. It is an intensive prolonged, often lifelong service. These people with cognitive disabilities, you know, do not get better, do not get well, so they often need supported decision making lifelong, and for the participants that we worked with, they did not have informal supports and were not likely to probably build their network of supports because of their disabilities, because of behaviours, because of mental health, all of those sort of issues. I think there's also a big misunderstanding of what decision support actually is and what it covers. People don't know where to find decision supporters, and to be honest, I wouldn't. I knew that we had a service, but I wouldn't know where to find one now." - Advocate [724]*

Access to funded decision supports

Many people rely on family members, friends and others to provide assistance in making decisions. For some people, however, having support independent of family may be more suitable. Others have limited informal support and require more formal assistance. Support can come in many forms, from support networks (e.g. circles of support) to more formal independent decision-supporters.

Access to appropriate decision supports for participants has been variable. Some participants have been able to access funding to establish circles of support but have struggled to get ongoing

funding once the supports have been established. Others have been denied access altogether on the basis that it did not provide value for money.

> *"...the microboard stuff was denied in my son's plan because they class it is not being 'value for money'. But if you know what it actually is, it is value for money, because you're creating seven to eight people that are going to be non-paid supports for that person. So it is value for money." – Anonymous* [725]

The success of circles of support relies on skilled facilitators and coordinators who can ensure the effective functioning of a circle of support.

> *"You need to have exceptional communication skills, to keep drawing the focus back to the person's preferences and their ideas about what they think is important in their life, while also respecting the views of others who have a stake, like family and so on...." – Belonging Matters* [726]

These supports have been seen as capacity building and as a result funding is sometimes withdrawn over the course of time with the view that participants should become self-sustaining. Participants have not been able to access funded independent decision support and have relied on advocates to assist when conflicts arise in terms of decisions.

> *"Sometimes a person may not have any family or friends in which case they will rely on paid supports. Paid supports need to ensure minimum conflict of interest. There are not enough Independent Advocates to provide support for decision-making as it is not an advocacy issue. Support for decision-making for an NDIS participant in relation to NDIS supports should be covered by the NDIS." – Individual* [727]

The lack of access to funded independent support can have significant impacts on choices over services, with limited opportunities to explore options outside of current providers or housing arrangements. For some participants who are only receiving supports from a single provider, exploring other service options can become impossible. The lack of independent support also puts people at a higher risk for exploitation and abuse.

> *"Many providers responsible for accommodation, care and support coordination are not operating each part independently and in the best interests of the participant. Rather, there are countless examples of actions by providers that work in favour of the provider. Sometimes these conflicts manifest themselves covertly in ways such as failing to give participants full access to information and alternative support options, or the fact that other, safer or more suitable accommodation options are available to participants. In other cases, conflicted providers fail to advise participants of their rights or to provide support to identify and raise safety concerns."- SDA Alliance* [728]

In addition, the lack of access to funded support for decision-making can lead to the appointment of a public guardian. There has been an increase in guardianship applications across jurisdictions since the introduction of the NDIS.[729] In some cases, the appointment of a guardian is an

appropriate action and provides important safeguards. However, there are many cases where the guardian has been appointed to assist the participant to navigate the administrative complexities and the complexity of decisions in the NDIS.

We have heard that the use of guardianship, which results in substitute decision-making, could be reduced if people with disability had access to funded independent supported-decision-making services. The Office of the Public Advocate (OPA) (Victoria) noted that "It is likely that this positive shift towards more individualised service provision, requiring more decision-making and responsibility for service coordination and management by individuals, has increased the demand for substitute decision-making services for people with significant cognitive impairment who lack informal networks of support. OPA believes that the use of substitute decision-making could be reduced with improved access to and availability of advocacy and supported decision-making services for this group of people".[730]

> *"The absence of appropriate support can limit a participant's opportunity to participate in decision-making and can result in the unnecessary appointment of guardians. As noted above, an increase in the number of people for whom Public Guardians or Public Advocates are appointed has been observed following the introduction of the NDIS."- Australian Public Advocates and Guardians [731]*

Culturally safe decision supports are not available for First Nations people

There is a lack of decision supports available that are culturally safe for people from First Nations communities. There is a need for improved understandings of culturally appropriate, trauma aware and healing informed decision-making that respects and upholds shared or communal decision-making processes which may be more prevalent in some communities.

First Peoples Disability Network found that "This [supported decision making] is a sensitive and complex area... Once again, this must be led by community organisations which best understand aspects such as; local cultural norms and values, community and individual trauma and fear of authorities; informal family networks and current decision-making support and processes; and are aware of limitations around culturally competent services in local areas".[732]

4.3.2. Decision-making support needs should be identified through the needs assessment and funded through the budget

Decision support can take many forms and different approaches are needed to meet the diverse needs of participants. We are proposing that people with cognitive disabilities should have access to the decision-making supports they need through their reasonable and necessary budget.

The new approach to needs assessment should include an assessment of decision-support need and then participants will be supported to connect with appropriate supports through the Navigator. This is consistent with and underpinned by the broader changes recommended to introduce a holistic assessment of need to determine a whole-of-person budget for participants (see Section 2.2.2 and Recommendation 3).

Assessment of decision-support needs

The need for decision-making supports should be included as part of the needs assessment and the risk assessment (see Action 3.4 and Action 16.2). This should include a consideration of what risks might be present in the participant's life and what safeguards can be put in place in response.

In some cases this may highlight the need for decision-making supports. In addition, the needs assessment should include consideration of whether current decision-supports are working and whether the participant would benefit from funded access to independent decision support, or funding to assist with the development and maintenance of informal decision supports.

Participants who currently rely on family to provide support with decision-making should be given an opportunity during the needs assessment to explore how this is working for both the participant and their family. In some cases this arrangement may be found to be working well and lead to good support. In other situations it may be the case that independent support could reduce pressure on family members or provide a better opportunity for participants to explore options about other supports.

Budget allocations should take into consideration the level of need identified and funding will be included as part of the flexible budget.

Access to the funded supports required

The Navigator and Specialist Navigator (see Section 3.1.4 and Recommendation 4) would have an essential role in exploring support needs with participants and linking participants to appropriate supports.

However, for many participants their need for support may be much greater than what the Navigator or foundation supports can provide. Effective decision-support usually cannot happen in a one-off meeting but instead requires the development of trust and a deep understanding of a participant's preferences and circumstances.

Participants may need:

- Access to a skilled facilitator to assist in the ongoing delivery of a circle of support
- A participant with limited informal support may require access to a funded independent decision-supporter who can take time to get to know the participant and understand their needs and assist them to make decisions about their services and supports
- Access to independent decision-supporter to assist someone with complex communication needs living in a group home to ensure they have access to sufficient information, support and tailored advice to assist them in making decisions about their housing.

Need for funded decision support may change over time depending on the person's circumstances and life stage. As a result, the Navigator may need to support the flexible use of funding over time to be responsive to changing circumstances.

Some participants may benefit from funded supports focused on building social connections and informal networks. For example, circles of support or Microboards can provide people with

disability the opportunity to have a network of supporters who meet regularly and assist them in thinking about their goals and decisions. These models usually rely on a main supporter (often a family member) who is responsible for organising and supporting the circle of support. There are organisations that can assist with facilitating circles of supports or Microboards or provide training to supporters. Participants should be able to access funding for both establishment costs as well as to maintain these networks and to provide appropriate training to those taking part.

The Navigator should have a role in supporting participants to identify best-practice approaches to Microboards and other similar arrangements. They should also have access to resources and case-studies to support participants where this arrangement may be beneficial. However, ongoing facilitation and coordination of circles of support requires specialist skills and would not be an appropriate role for the Navigator. The time involved in coordination would also exceed what was possible based on the proposed workload of the Navigator.

> **Box 29: Using networks to assist with decision-making | Circles of Support and Microboards**
>
> Circles of support or Microboards are often used by people with disability and families to assist with decision-making. These are voluntary networks of people who come together to provide practical advice, problem solving, generating ideas and assisting with high-level decisions.
>
> Some circles of support are facilitated by providers though many are facilitated by a family or friend. Circles of Support can assist in a range of ways including by building a sense of community, and broadening the informal network of support beyond immediate family. Some participants utilise NDIS funds to assist in the set-up or maintenance of these networks. It can be beneficial for people who are participating in these networks to access training and support to help them in their role.
>
> > *"Circles of support can also assist with building the individual's capacity to make informed choices whilst weighing up the dignity of risk. Everyone needs a support network to function well in their daily lives. For people with disability this needs to be more structured so that individuals can achieve their goals and have people looking out for their well-being. Intentional support networks are key to keeping people safe and supported into the future, especially after parents may no longer be able to." - Family Advocacy*[733]

Some participants, particularly those with little or no informal supports, will benefit from access to individual independent support for decision-making. Putting this support in place may reduce the need for substitute decision-making arrangements such as guardianship.[734] Independent decision-supporters must be independent of other providers used by the participant and should not be an individual advocate. These independent decision supporters should support participants to consider options outside of existing service arrangements.

This approach would enable participants to have opportunities to explore different service offerings and make informed decisions about the supports they receive. They would also create natural safeguards for participants who do not have informal supports.

> *"While many Participants who need support for decision-making have family, friends or other informal supporters who are able to assist, not everyone has someone in their life who they would like to support them with decision-making, or someone who is willing or able to provide this support. For these Participants, decision-making support would be a reasonable and necessary support and should be funded in their NDIS plan. This would help to increase the participation of Participants in the decision-making process." – Australian Public Advocates and Guardians* [735]

It is essential that there is appropriate oversight over independent decision supporters to ensure that they are assisting participants to make decisions which align with their will and preferences. Independent decision-supporters should be required to be registered providers in line with the revised regulatory framework (see Recommendation 17).

The National Disability Supports Quality and Safeguards Commission should support an uplift in service quality including by providing information about what good quality support for decision-making looks like in different contexts. The Navigator should be responsible for working with the participant on a regular basis to review whether the decision supports are appropriate and to help participants to change their supporter as needed.

Ensuring culturally safe decision supports

Further work is needed to better understand how best to support First Nations participants with decision-making support. There are differing cultural understandings of how decisions are made which are often at odds with a mainstream approach to supported decision-making. The lack of research on supported decision-making in First Nations communities adds to the challenge of ensuring appropriate, culturally safe supports.

However, it is critical that action is taken to better understand and support First Nations people and to prioritise those disproportionately impacted most by substitute decision-making and guardianship orders.[736]

First Peoples Disability Network found that "How, and by who, decision-making support is provided for First Nations peoples with disability at different points on their NDIS pathway, requires careful and informed consideration."[737]

A specific First Nations Framework for Supported Decision Making should be developed in partnership with First Nations people with disability. This should consider the different contexts and cultural understanding of decision-making to determine the best approach for providing decision-making support. It should inform the work of the Navigators in connecting people with supports that are appropriate to them and how Needs Assessors consider need across intersectional and cultural contexts.

4.3.3.   Action & Implementation Details

Action 5.3: The <u>National Disability Insurance Agency</u> should include an assessment of participants' need for independent decision-making support as part of budget setting and ensure participants can use their NDIS budgets to access independent decision-making supports

Need for decision-making supports should be assessed as part of the process of determining a budget (see Action 3.4) and the risk assessment and safeguard building process (see Action 16.2). This should include supports for participants to build and maintain decision-making support networks and access independent decision-supporters where required. Where participants with little or no informal supports receive funding for decision-making supports, this should be provided independently of other service provision to embed natural safeguards and ensure participants are able to consider different models of support and housing. Information must be available to participants, nominees, and Navigators about options to purchase supports for supported decision-making with NDIS budgets. Participants should be allowed to use their NDIS budgets to fund independent decision-making supports and establish decision-support networks (such as circles of support). Independent decision-supporters should be NDIS providers and required to be registered, consistent with the broader regulatory model (see Recommendation 17).

Implementation detail:

- The National Disability Insurance Agency through its needs assessment process for budget setting (see Action 3.4) should include an assessment of the need for independent decision-making support

    - This should ensure that this need (when identified) is incorporated into the budget for the individual

    - Navigators and Specialist Navigators should be informed where this need has been identified through the needs assessment and provide the participant or nominee with information about options to purchase supports for supported-decision-making with their budget

- The National Disability Insurance Agency should undertake further work to identify the best approaches to ensure access to culturally appropriate decision-making supports for people from culturally and linguistically diverse and First Nations communities

    - This should reflect a recognition that differences in cultural understanding of disability and decision-making will impact on how support for decision-making can best be provided.

4.4. People providing decision-support need access to training and support

People with cognitive disabilities often rely on others to provide support with making decisions. Providing effective decision support is a complex task that requires knowledge about the person being supported, a trusted relationship, time, experience and skill.

Unfortunately, there is currently inadequate support, training and information available to help decision-supporters perform this role. This means supporters are not always able to be as effective as they could be.

Decision-supporters should be given access to high quality training, support, advice and best-practice, evidenced-based information. This would help participants get better quality decision support and reduce substitute decision-making.

4.4.1. Decision supporters don't currently have access to training and information

Participants who require support for decision-making access support in many different ways. It is often presumed that supporters such as family members, friends or providers will have the skills and understanding to support-decision-making appropriately. However, providing effective decision-support requires expertise, experience and time to be able to provide balanced support which allows dignity of risk. It also requires the person providing support has a good understanding of the person, their circumstances and their preferences.

> Box 30: La Trobe Support for Decision Making Practice Framework:[738]
>
> Professors Christine Bigby and Jacinta Douglas from La Trobe University developed a framework for supported decision-making which helps to unpack the various components involved in support a person to make a decision. This framework highlights the many different steps required to be an effective decision supporter and illustrates why specialist skills and training is required to be effective.
>
> *La Trobe University framework for supported decision-making*

Figure: Steps involved in supporting a person to make a decision

1. Knowing the person
2. Identifying and describing the decision
3. Understanding the person's will and preferences for the decision
4. Refining the decision and taking account of constraints
5. Consider if a formal process is needed
6. Reaching the decision and taking accounts of constraints
7. Implementing the decision and seeking advocates if necessary

There is little support for family members and other supporters as decision-supporters

People with cognitive disability often rely on family members and other supporters to assist them in making various decisions about their lives. These informal decision supporters are well placed to provide this support given their knowledge about their person and their trusted relationship.

> *"NACBO [National Alliance of Capacity Building Organisations] strongly supports the notion that people with disability should lead their own lives. For many people this requires the heavy investment of families to support their loved ones to attain the life they want. Family, in this respect are well placed, have less vested interest, also knows the person the best and their relationship usually endures over the lifetime. They can also act as an important safeguard when things don't go according to plan. When invested in with good capacity building they can hold a strong vision for ensuring their family member has access to the good things in life, even go against the tide and push back against low expectation, and poor service responses." – National Alliance of Capacity Building Organisations [739]*

However, this does not mean it is easy for families. Providing decision-support to a family member can be a very complex role. It can be difficult for families to recognise differences between what the person with disability may want and what the carer or family thinks would be best for them. Without support or training, families may be unclear about best-practice and how to balance

supporting choice and managing risk. In addition, as parents age they may need others (including siblings) to take on some of these roles or to have additional assistance in providing support.

Support for decision-supporters has not kept pace with the increased demands of the NDIS. Families and other decision-supporters do not have access to the training, information and resources they need. This can lead to substitute decision-making, where people are making decisions on behalf of the person with disability, occurring either informally or formally through a guardianship order.

> *"Mum's known me for so long she sees my disability as more visible than other people can. She thinks she should be the one that's mainly in charge of decisions. I want her to see other people's point of view of how I can be more independent. It broke my heart when I was 15 and mum said because of your disability I could never really see you working in a group home or independently. She doesn't think I could cope with sharing space with another person." – Participant* [740]

> *"The absence of appropriate support can limit a participant's opportunity to participate in decision-making and can result in the unnecessary appointment of guardians. As noted above, an increase in the number of people for whom Public Guardians or Public Advocates are appointed has been observed following the introduction of the NDIS." – Advocate* [741]

There is little support for workers in decision-making

Support workers or other paid staff also play a role as decision-supporters, even if they are not in a formal decision-support role. Workers will support people to make decisions about what they eat, how they spend their day or what activities to participate in. This is often seen as a normal part of their work. Despite their critical day-to day role few have formal training in best-practice decision-support.

The NDIS Code of Conduct requires workers and providers to "act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with relevant laws and conventions".[742] The requirement to provide support for decision-making is further developed in the NDIS Code of Conduct - Guidance for Workers which outlines the requirements of disability workers to work directly with the person with disability, wherever possible in regards to decisions. It also acknowledges the role of children in being involved in decisions, appropriate to their age.[743]

Despite this guidance, we have heard that many workers have difficulty balancing issues around the person's autonomy and managing risk in their role. They also have to balance preferences and views of families as well as their responsibilities to the participant.

Workers report overriding the preference of the person they are supporting when they thought there was a risk of harm or had concerns about professional liability or other consequences.[744] Participants have also told us of their experiences where they felt disability workers were not listening to their preferences.

> *"When I was with (service) they put me with… someone totally new who didn't know my needs at all. This upset me because I did not trust the new person because they*

were controlling me as if I was a 12-year-old. For example cutting off time 9 pm to be on the phone. The support worker said you have one hour to be on the phone then it's off and then we're going for a drive in the car. I didn't feel comfortable. I told the coordinator at the house that I felt uncomfortable." – Participant [745]

There are a range of factors that impact on the quality of decision-support provided by support workers, including access to training, impact of time pressures, and challenges around managing rights, practicalities and risk.[746]

Researchers have found that decision-supporters in some cases are actively shaping the information they provide to people in order to encourage the choice that they believe is in the best interest of the person.[747] Other studies have found that some support workers are unaware of the impact of their own preferences and values on their support. This limits their ability to provide unbiased support.[748]

> *"Just say a client was choosing the colour of which to paint their room, the influencer might influence based on their own personal preference, not based on what they know the client prefers. You need to live in that room every day, so this matters." – Participant [749]*

There are a number of resources available to assist decision-supporters to develop their skills. Some of these resources are targeted at families and informal supporters while others are targeted towards disability workers. The issues are different for each. However, most decision supporters are unaware of these resources and unclear about what support they need to perform their role well.

For example, the La Trobe Decision Making Framework (see Box 30) and associated e-learning resource covers principles and strategies to support decision-supporters. Several ILC projects also had components of training for decision-supporters, including Inclusion Australia's Making Decisions Real project and Western Australia's Individualised Services project on capacity building for people with complex communication needs.

The NDIA Supported Decision Making Policy recognises the importance of decision-supporters and the need to connect decision supporters to training and information to build decision supporters knowledge and skills. The associated implementation plan includes a specific action to "Build the skills and knowledge of decision supporters to recognise and enable the will and preference of participants in decision-making".[750] The policy provides an important first step in improving access to supports. However, further work is needed to ensure that this approach is appropriately actioned. Feedback from families and advocates to date suggests that people are still struggling to get access to the support they need.

> *"The ADC [NSW Ageing and Disability Commission] has welcomed the introduction of the NDIS Supported Decision Making Policy, to uphold the right of participants to make their own decisions, including in relation to NDIS services and supports. Among other things, we are pleased to see a commitment to make supported decision-making part of NDIS policies, systems and processes, and adoption of the National Decision*

Making Principles. However, in our experience there is significant work to be done to gain alignment between policy and practice. In particular, we regularly identify participants who are not involved in any meaningful way in their NDIS planning or review meetings."- NSW Ageing and Disability Commission (ADC) [751]

4.4.2. Decision-supporters should be provided with better information and training

We propose that both informal and formal decision supporters receive much greater access to the information and training needed to support participants with cognitive disabilities. This is an essential step to ensure that high-quality support is available for all participants who may benefit from supported decision-making.[752]

Support for families and other informal supports acting as decision-supporters

Informal supporters require access to high-quality training and information about supported decision-making. Many families want to do the right thing, but have not had the opportunity to access formal supports; "Parents and others want to know what it is, and formally, how they might do it – even if they've always done it intuitively".[753]

In the future, evidenced-based resources and training for supported decision-making should be available through foundational supports. This program of work should include the development of co-designed tailored training for families and other supporters, support workers, Navigators and NDIA staff.

Navigators would play an important role in ensuring participants and families can access the supports they need in relation to decision-making. Navigators should explore what supports are in place for decision-making as well as what additional support can be provided. As part of this, Navigators should link informal decision-supporters to appropriate training, information and peer-support to help them develop their skills and provide appropriate support. They should also follow up with families to see if they have used the training suggested and to determine what other supports they may need. Families may need pro-active support to assist them in accessing the right resources and training: "I often ask people - have you seen that website? It talks about supported decision-making. Nah. Or, nah, it didn't make sense to me. So, I understand there's some really good ideas behind all that, but it's how do you get to the person in a sufficient format that they can start to at least grasp what's being offered here".[754]

As part of their check-ins, Navigators should discuss with participants what level of involvement they have in decision-making about their lives and what needs to change to improve this. Navigators can play a role in supporting participants and families to raise and address concerns that they may have around the delivery of decision-support by providers. A critical element to the success of this approach includes ensuring Navigators have a good understanding of best-practice support for decision-making.

Consideration should be given to the additional support required for people with complex communication support needs and individuals from diverse cultural backgrounds or First Nations

communities. This must include an understanding of different cultural approaches to decision-making.

Information and training for support workers

There have been several projects which have tried to build the capacity of support workers. These projects have revealed the depth of need for information and training. Advocates describe the work that they currently do trying to build understanding amongst providers and others about decision support:

> *"We spend a lot of time educating service providers and others around what the rights are of the person, what decision support is, and what the requirements and how they might differ to what the service provider is requesting... we often, we have a number of requests along those lines... a lot of education needs to take place... with service providers and the NDIS, and others." – Advocate [755]*

The new National Disability Supports Quality and Safeguards Commission should provide clear information about the roles and responsibilities of support workers and providers in relation to support for decision-making.

In particular, the National Disability Supports Quality and Safeguards Commission should provide guidance regarding the obligations both providers and workers have against the code of conduct in relation to acting with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with relevant laws and conventions.[756] This should go beyond what is currently provided in the NDIS Code of Conduct Guidance and provide practical examples and assistance about what is required.

All support workers should have access to training and resources about support for decision-making and this training should be included in the induction for all new support workers. The National Disability Supports Quality and Safeguards Commission should assist in promoting the training and any e-learning modules on supported-decision-making for support workers to assist them in their role.

> *"We need to be able to have access to training for the people that spend the most time with our people, which are usually support workers. Yep. If say for instance, they were under an organization more training for organizations and to prove that they are using those techniques of supportive decision making." – Carer [757]*

4.4.3. Action & Implementation Details

Action 5.4: The Department of Social Services, the new National Disability Supports Quality and Safeguards Commission and National Disability Insurance Agency should ensure decision-supporters have access to information, training and resources to assist them in providing best-practice support for decision-making

Navigators should link decision-supporters to information and training to assist them in their role. They should also guide participants to access decision supports to ensure the participant is involved in decision-making and are supported to access capacity building foundational supports (see Actions 5.1 and 5.2). To enable this, Navigators should have access to a central repository of curated evidenced-based resources and training coordinated by the Department of Social Services.

Implementation detail:

- The National Disability Insurance Agency must ensure the Navigator and Specialist Navigators have proactive discussions about support for decision-making with all participants with cognitive disabilities and complex communication support needs, as well as their families or supporters. The Navigator and Specialist Navigators should guide participants and families to ensure that participants are involved in decision-making about the supports they access through their budget.
- The NDIA must ensure that all informal decision supporters have access to high-quality information and guidance materials to assist them in providing best-practice approaches to supporting decision-making.
- The NDIS Commission must promote best practice and quality support for decision-making for both independent decision supporters and support workers.
- Australian governments through capacity building foundational supports (see Action 1.1 and 1.3) should:

  - Develop a central repository of curated evidenced-based resources and training for best-practice supported decision-making and the promotion of evidenced-based resources.

  - Establish a training program for both formal and informal decision supporters to assist them in fulfilling their role. This training needs to include information about disability rights, dignity of risk, and managing conflicts between the views and preferences of the participant and the decision-supporter.

4.5. There is a lack of rigour to the appointment, support, and oversight of nominees

Nearly half of participants with intellectual disability (including Down syndrome) have a nominee in place who is empowered to act on their behalf of or make decisions for the participant.[758] Given this, nominees have a significant amount of power in the NDIS. It is critical that the rigour of appointing and overseeing this role is proportional to its power. Nominees must also be set up appropriately to successfully work in the interests of the person they represent.

Under the current system, nominees are put in place without appropriate consideration of risk or suitability of the nominee and with minimal oversight. Nominees are not provided with enough

information and support to carry out the responsibilities of their role. There are also complexities with how the nominee arrangements interact with other appointed substitute decision-makers.

A refresh of nominee arrangements is required. This should include a more rigorous approach to appointing nominees, ensuring access to support for those in the role, and more ongoing and appropriate oversight.

4.5.1.   Nominees are regularly put in place without any review, support or oversight

In some cases, the use of nominees works well, and nominees act according to best practice approaches to supported decision-making. However, the design of the nominee provision leaves it open to misuse and there remains potential for abuse of participants.

Current approach to nominees

The complexity of the NDIS and the support needs of participants means the NDIA requires a mechanism to allow for a representative to act on behalf of the participant. The majority of participants require support with decision-making and many of these will likely require support interacting with the NDIS and with providers.[759] This can involve financial management activities (as part of managing NDIS funding) and legal matters (as part of negotiating and signing service agreements to access supports)

In order to address this issue, the NDIS has put in place substitute decision-making arrangements which are separate to state based guardianship laws. Under the NDIS Act, there are two types of nominees – plan nominees and correspondence nominees.

A plan nominee can be appointed to make decisions about the participants plan and/or the management of funding and signing of service contracts. The nominee can act to the extent specified in the instrument of appointment, noting that the CEO or delegate can limit the matters that a plan nominee is appointed to deal with.

A correspondence nominee cannot make decisions about the participant's plan but can request information from the NDIA or receive letters on behalf of the participant.

Nominees can be appointed for a set period of time or indefinitely. NDIS guidelines on nominees outlines the duties of the nominee to the participant which include: [760]

- Understand the participant's wishes
- Promote the participant's personal and social wellbeing
- Consult with other people in the participant's life
- Build the participant's skills to make decisions
- Avoid or manage conflict of interests.

Concerns regarding the power of nominees

Nominees are often appointed to facilitate administrative interactions with the NDIS and providers, but not necessarily to act as substitute decision-makers. However, concerns have been raised about

whether the current approach is appropriate as it provides the nominee with the power of a substitute decision-maker.[761]

> "The NDIA's own use of nominees is problematic and is often used because it is easier for the NDIA to communicate with someone other than the participant. We assume we do not need to spell out the risks when the NDIA: Appoints a third party (e.g. family member or provider) as NDIS nominee, Does not meet with the participant at all, Funds supports based on the input of the nominee, Allows the nominee to then make decisions about using the funding under the plan. We note the Framework states that if a person needs supported decision making, that this can be funded through their plan - we have never seen this happen." - Villamanta Disability Rights Legal Service [762]

> "I think that the current nominee system is really poorly designed to support decision making... I'm shocked by how much power I have. I have a huge amount of power. I can essentially exclude my brother from the (planning) meeting. I can basically dictate things. I could focus solely on trying to get him day program access, even if he doesn't want that or has never had an opportunity to explore an alternative. There's a problem with the policy, it's not, it's not right, it doesn't fit with the values and principles in the legislation."- Nominee [763]

Some advocates, as well as the Australian Law Reform Commission, have suggested that the nominee role should be reformed to introduce an additional category of decision-supporter to address the issue of the nominees being both a supporter and in substitute decision-making role.

The Office of the Public Advocate indicated that "To blend the role with substitute decision-making under one appointment can cloud the responsibilities of a plan nominee who is afforded the ability to move from one role to the other with little to no oversight. Without appropriate clarity and safeguards around substitute decision-making for plan nominees, there is potential for unnecessary restrictions to be placed on a participant's decision-making authority".[764]

Similarly, the Australian Law Reform Commission in their inquiry 'Equity, Capacity and Disability in Commonwealth Laws' (ALRC Report 124) suggests changes are required to the existing nominee categories: "The existing NDIS nominee scheme should be replaced with a scheme for 'supporters' and 'representatives', as described in Chapter 4. In particular, the NDIS Act, Rules and Operational Guidelines should be amended to provide a mechanism for the recognition of supporters appointed by participants and representatives. In effect, the reforms would result in the current 'correspondence nominee' role being subsumed by the supporter role and plan nominees being replaced by representatives".[765]

Appointment of nominees

Nominees have significant powers and therefore should be subject to appropriate checks as part of the appointment process. Currently a participant can request a nominee be appointed and the NDIA actions this without rigorous consideration of risk and suitability of the nominee.[766] In

addition, there is no assessment of what support a nominee might require in their role. NDIA Operational Guidelines indicate that if a participant asks the NDIS to appoint a nominee they will usually appoint one. [767]

In order to determine if the nominee is appropriate, the NDIA indicates that it will check:

> Whether the participant has freely chosen the person to be nominee
> Whether there is a conflict of interest (e.g. the nominee is a provider).

It is notable that the Operational Guidelines do not include a consideration of other factors that are critical to whether an appointment is appropriate and does not pose significant risk to the participant. Some of the factors that should be considered to improve the rigour of the appointment process would include:

> Nominee's understanding of the role and their duties in that role
> Suitability of the nominee (their capacity to meet the duties including providing support for decision-making and providing timely support)
> Need for a nominee (capacity of the person to make their own decisions with support)
> Risk assessment
> Management of family conflict (where there is dispute about who will be the nominee).

> *"There is also a need for greater rigor in the appointment process, to ascertain whether the nominee understands the role and is able to fulfil it, including supporting the participant's decision-making. A range of reports to the ADC involving neglect of participants by family or informal carers have involved NDIS nominees who have not had the capability to act in the nominee role, are blocking services, and/or are making decisions for the participant that are not based on the participant's will and preference." - NSW Ageing and Disability Commission [768]*

This approach to appointing a nominee in the NDIS is in stark contrast to the highly rigorous appointment process of a Guardian under state and territory legislation, which requires a tribunal hearing and evidence about the suitability of the Guardian.

Support for nominees

Nominees are given minimal information and support after their appointment. Once the nominee has been appointed, the NDIA issues an instrument of nominee appointment and sends a copy to both the participant and the nominee. This document includes information about who has been appointed, the type of nominee, what the nominee cannot do and the length of the appointment.

Nominees are not provided with information, training, support or guidance, beyond the instrument of appointment, about how to execute their duties. The Nominee Rules note that it is expected that the Agency will assist nominees in regard to supporting the capacity of the participant, but there is no clear approach for implementing this support.[769]

Nominees are left to identify how to fulfil these duties with little or no support, information or training to carry out these important duties, and in some cases a lack of awareness of the requirements of their role.

> *"I barely remember the day that I was made a nominee, there was that little information shared with me. I just made that nominee and then I didn't receive a phone call being like, so how's your nominee role going? What kind of support do you feel like you would need? Here are some videos of how nominees have assisted their people, nothing, nothing. I'm sure some those resources might be out there, and I know that the NDIA is doing some work on trying to look at the nominee role and how they can support them, but up till this point there's been no monitoring and capacity building, and I know it's been identified as a big issue." – Nominee* [770]

> *"Nominees need to receive training in best practice in supported decision-making and a nominee monitoring, review, and complaints process should be implemented that is centred on meaningful engagement with the participant, again, free of the nominee's presence." - Queenslanders with Disability Network* [771]

> *"Sometimes the decisions that are made do not reflect the preferences of the person with intellectual disability. Decision supporters need to ensure they include the person with intellectual disability in the decision making process and that they have a strong understanding of the persons rights." - South Australia Council of Intellectual Disability* [772]

Ongoing oversight of nominees

While many nominees are doing the right thing, there is little oversight to identify when nominees are not making decisions in the best interest of participants. In some cases a nominee may be the only person in the participant's life (outside of providers). This puts the nominee in a position where they can use their powers to perpetrate abuse or cease needed services.

> *"I've come across quite a few times this year. I've been supporting someone with an intellectual disability who has a nominee, but their nominee is not listening to their will and preference, and the providers are listening to the nominee over the person who is receiving the supports. I've talked to the NDIS about this, and the NDIA, and asked about getting people removed as a nominee, and they've just said it's not up to them; it's so difficult." - Individual advocate* [773]

Nominees can be cancelled or suspended if the NDIA becomes aware that the nominee is not complying with their duties or acting in the participants best interests. Participants are able to contact the NDIA if they have concerns about their nominee, but there is no regular check-in to determine the appropriateness of the nominee arrangements. It is difficult for participants to make a complaint about their nominee due to the complexity of the system and most people being unaware of their rights.

The NSW Ageing and Disability Commission provided a powerful case study which outlines the extent to which things can go wrong when a nominee is not acting in accordance with the interests of the participant.

Case Study 10: Nominees | NSW Ageing and Disability Commission

"The ADC [NSW Ageing and Disability Commission] received a report raising concerns about a woman with intellectual disability who had significant NDIS funding for daily supports. The participant's brother was blocking her access to NDIS services and being aggressive towards workers, despite the participant explicitly requesting more support. Parts of the participant's plan were plan-managed, and her plan nominee was her ageing mother. However, her brother was able to contact the NDIA and make himself the plan nominee without any involvement of the participant or her mother.

The ADC [NSW Ageing and Disability Commission] worked with the participant's existing providers to meet with her, and made inquiries with the NDIA that raised concerns about fraudulent spending of the NDIS plan. The information revealed that:

1. There were large claims submitted by a provider, despite no evidence that the supports had been provided. The participant confirmed that she had not received the supports.
2. An SDA funding application that had been submitted for the participant was linked to a provider and property that had the same residential address as her brother.
3. The participant had funding for Support Coordination, and the NDIA held information that this support was being provided by the same service that was linked to her brother. However, the NSW Ageing and Disability Commission found no evidence that Support Coordination was being provided, and the participant confirmed that she had not received this support.

In discussions with the ADC [NSW Ageing and Disability Commission] about decision supports, the participant explicitly said she did not want her brother involved in any decisions about her plan. The ADC [NSW Ageing and Disability Commission] supported the participant to change her NDIS plan to agency-managed to enable increased oversight of her plan; to remove her brother as her plan nominee; and to access a new Support Coordinator to connect her with her preferred choice of providers."[774]

Nominees and other appointed decision-makers

In addition to these issues, there are also complexities with how the nominee arrangements interact with other government appointed substitute decision-makers. Currently under the NDIS Act, there is limited recognition of the role of an appointed guardian or attorney with relevant powers. Unless appointed as nominee, guardians are not recognised under the legislation as being able to make decisions about a participant plan.

It can be problematic where a participant requires a nominee but already has someone legally appointed to assist with decision-making as NDIS nominee provisions do not interact well with other substitute-decision-making regimes.

The NDIA indicates that it will discuss with other appointed decision-makers what decisions they are already supporting the person with. This is to determine if they should be appointed as nominee. If the role is different, the NDIS will discuss with them who else might be appointed. In some jurisdictions, there are questions as to whether other appointed decision-makers have the legal authority to perform the role of a plan nominee.

The 2019 Tune Review acknowledged the need to review the nominee provisions of the NDIS and their interaction with guardianship and administrative legislation in the States and Territories.[775] However, little progress has been made in addressing the conflict between nominee provisions and other substitute decision-makers. Advocacy organisations as well as the Public Guardians have clearly expressed the challenges which result from the different approaches to substitute decision-making.

> *"There is also no requirement, in the provisions concerning the appointment of nominees, for the NDIA to consider appointing people already appointed by participants to make decisions for them under enduring powers of attorney (or comparable instruments). A proposed solution to this lack of fit between NDIS nominee provisions, and State and Territory substitute decision-making laws, would be to recognise guardians and attorneys, to the extent and for the period articulated in their appointing instrument, as having the same ability to take actions on behalf of participants as Plan Nominees (without being appointed as Plan Nominee)." –*
> *Australian Public Advocates and Guardians [776]*

4.5.2. There needs to be more oversight of the appointment of nominees and support for nominees in their role

Nominees can play an important role in supporting participants with cognitive disabilities to assist with the significant administrative burden of the NDIS, to advocate on their behalf, and to be able to access self-management.

Realising these benefits and mitigating the risks of nominees requires a package of responses. We are proposing some immediate reforms as well as others that will require further work particularly in the most complex areas. The changes include:

- Further work with participants, families, advocates and nominees to consider potential changes to the nominee categories that have been raised to support a rights based approach to supported-decision-making
- Amendments to the approach to appointment of nominees to ensure nominees are suitable and address any potential risks in their appointment
- Additional support for nominees to assist them in executing their role
- Introduction of oversight mechanisms for nominee provisions
- Further work with states and territories to address the conflict between current nominee provisions and other substitute decision-making arrangements.

These changes will support participants to continue to utilise nominee arrangements to support the interaction with the scheme, while also addressing current issues with the approach.

Separating substitute decision-making from supported decision-making

The NDIA should work with participants, families, advocates and nominees to consider if any changes are required to the nominee provisions to ensure they are consistent with a rights based approach to supported decision-making. It has been proposed by some advocates that there is a need to differentiate between providing support to the participant to interact with the scheme and to make decisions and the power to make substitute decisions.

One approach to address these different requirements would be to create a new category of nominees in addition to plan nominees and correspondence nominees. This category could be referred to as supported-decision-making nominee and have the power to interact with the scheme and provide decision-making support but not be a substitute decision-maker.

It is also possible that the current nominee categories could remain in place with improved approaches to supporting nominees to engage in supported-decision-making. Options around new approaches to nominees need to be considered carefully to avoid adding complexity or administrative burden to already complex lives for participants and their families or to the scheme.

Appointment of nominees

The process of the appointment of nominees should be amended to include an assessment by the NDIA of:

- The participant's need for a nominee (capacity of the person to make their own decisions with support)
- The nominee's understanding of the role and their duties in that role
- The nominee's suitability (their capacity to meet the duties including providing support for decision-making and providing timely support, and an assessment of risk)
- The participant's view of the suitability of the proposed nominee including an opportunity for the participant to speak to NDIA staff without the proposed nominee present (with appropriate support).

Support for nominees

Once nominees are appointed they should be provided with additional information and support to assist them to execute their duties. This should include:

- A requirement to complete evidenced-based training on support for decision-making
- A contact at the NDIA for advice on any complex matters or concerns that arise
- Case studies and information which provide examples of how nominees will act to support participants to be involved in making decisions about their supports.

Improving the appointment and on-boarding process for nominees should improve the quality of the support provided by nominees and ensure that nominees are able to enact the duties as

outlined by the Nominee Rules. It is important that this process does not create an overly burdensome approach which creates barriers to participants putting nominees' in-place.

As part of their regular check-ins with participants, Navigators should check-in with nominees about their role and how the nominee is supporting the participant in decision-making and capacity building. This would provide an opportunity to link the nominee to information, support and training as required. Participants should be involved in meetings with Navigators where possible even when a nominee is in place.

Oversight of nominees

There should also be a regular review of nominee appointments, including indefinite appointments. This review should include information from the participant, providers and others who interact with the nominee to gauge whether the arrangements are working as they should. Particular attention should be given to reviewing arrangements where the participant has limited other informal supports or social connections. Participants should be supported to understand their rights in relation to nominees and to understand the process of raising concerns if they feel the nominee is not taking their views into account.

This approach to oversight will take a measured response which will ensure that the NDIA provides appropriate oversight to reduce the risk of inappropriate use of nominee powers while not interfering with the important role that the nominee currently undertakes for many participants. This approach should be proportionate and risk-based. The frequency and depth of reviews should reflect risk factors, as well as random reviews to test whether the risk factors being monitored are effective.

Addressing the conflict between other substitute decision-making approaches

It is critical for government to address the current conflict between nominee provisions and other substitute decision-making appointments. It is untenable for participants to have to seek another appointment (e.g. nominee) just for purposes of interacting with the NDIS when they already have a guardian or other substitute decision-maker in place. The current approach has led to challenges for guardians, participants and their nominees.

In addressing this issue, the Department of Social Services should work with state and territory governments, participants, advocates and nominees. This work should include a consideration of the recommendation by the state/territory Guardians and Public Advocates to recognise guardians and attorneys, to the extent and for the period articulated in their appointing instrument, as having the same ability to take actions on behalf of participants as Plan Nominees (without being appointed as Plan Nominee).[777] A potential change to the NDIS Act that should be considered by this work program may include the following provisions:

- A person who is appointed by a Court or Tribunal, or who is appointed by a participant under an enduring instrument (such as an enduring power of attorney), who has power to make decisions for a participant and whose responsibilities in relation to the participant are relevant to the duties of a nominee, is hereby recognised, to the extent and for the period that the

appointing instrument allows, as having the same ability to take actions on behalf of a participant as a nominee appointed under section 86 or section 87.

- A person who is appointed by a Court or Tribunal, or who is appointed by a participant under an enduring instrument (such as an enduring power of attorney), who has power to make financial decisions for a participant, is entitled upon request to inspect the participant's plan where this is relevant to the performance of the appointed person's duties.

These proposed changes would also need to be accompanied by a policy change such that the NDIA avoid the appointment of a plan nominee when there is already an appointed guardian or attorney with relevant powers.

Further work needs to be done to ensure that this approach will not lead to any unintended consequences. We recommend that the Department of Social Services work in partnership with participants, nominees, state and territory governments, guardians and advocates to address the current conflict in the arrangements and to develop a seamless approach to substitute decision-making, where it is required.

4.5.3.   Action & Implementation Details

📄 **Action 5.5: The National Disability Insurance Agency should reform the approach to appointing nominees, provide improved training and information to nominees, and increase oversight of nominee decisions**.

The NDIS Nominee Rules should be reformed to ensure there is a more rigorous assessment of the need for and suitability of a nominee prior to appointment. Once appointed, the nominee should be provided with information, evidence-based training, and guidance for complex matters or concerns. This should ensure they fully understand their role and responsibilities and are supported to perform their role consistent with the participant's will and preferences.

To improve oversight of decisions, the Navigator should undertake an ongoing monitoring role of nominee appointments, as part of a more structured review process to be conducted by the National Disability Insurance Agency (NDIA), to ensure participants and family are getting the support they need to make decisions about the NDIS.

The Department of Social Services should work with state and territory governments, participants, advocates and nominees to address the conflict between other substitute decision-making schemes and nominee appointments. Consideration should be given to changes to the NDIS Act and NDIS Rules to recognise guardians and attorneys, to the extent and for the period articulated in their appointing instrument, as having the same ability to take actions on behalf of participants as plan nominees (without being appointed as plan nominee). In the event of a conflict between an appointed guardian or attorney and a plan nominee, the NDIA should consider removing the plan nominee, for the duration of the appointment of the guardian or attorney.

Implementation detail:

- The NDIA should reform the NDIA Nominee Rules regarding appointment of nominees to include an assessment of:

  - The participant's need for a nominee (capacity of the person to make their own decisions with support)

  - The nominee's understanding of the role and their duties in that role

  - The nominee's suitability (their capacity to meet the duties including providing support for decision-making and providing timely support, and an assessment of risk)

  - The participant's view of the suitability of the proposed nominee including an opportunity for the participant to speak to NDIA staff without the proposed nominee present (with appropriate support).

- The NDIA should provide all nominees with information about their roles and responsibilities and support to assist them to execute their duties. This should include:

  - A requirement to complete evidenced-based training on support for decision-making

  - A contact at the NDIA for advice on any complex matters or concerns that arise

  - Case studies and information which provide examples of how nominees will act to support participants to be involved in making decisions about their supports.

- The NDIA should establish an approach for Navigators and Specialist Navigators to conduct regular reviews of nominee appointments to ensure participants and family are getting the support they need to make decisions about the NDIS and to identify cases of misuse of nominee powers. This should be risk-based and proportionate.

- The Department of Social Services should work with state and territory governments, guardians and advocates, participants, and nominees to address the conflict between other substitute decision-making schemes and nominee appointments.

5. Better support for children and their families inside and outside the NDIS

- We have heard the approach to supporting children with disability or developmental concerns and their families is not working.

- This not just an issue for the NDIS. Around one in five children in Australia have disability or developmental concerns by the time they reach school.[778] This is a mainstream issue that requires a coordinated response across all service systems and governments.

- We use the age younger than 9 for early childhood to align with the change recently introduced by the National Disability Insurance Agency (NDIA) to reflect the World Health Organisation's definition of young children (0 to 8 years of age).

Recommendation 6: Create a continuum of support for children under the age of 9 and their families

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📑 Legislative change required

- Action 6.1: <u>National Cabinet</u> should agree to jointly invest in a continuum of mainstream, foundational and specialist supports to address the needs of all children with disability and developmental concerns.
- 📑 Action 6.2: The <u>National Disability Insurance Agency</u> should reform the pathway for all children under the age of 9 to enter the NDIS under early intervention requirements.
- 📑 Action 6.3: The <u>National Disability Insurance Agency</u> should introduce a more consistent and equitable approach to assessing developmental delay.
- 📑 Action 6.4: The <u>National Disability Insurance Agency</u> should change the basis for setting a budget to a whole-of-person level, and introduce a new needs assessment process to more consistently determine the level of need for each child and set budgets on this basis.
- 📑 Action 6.5: The <u>National Disability Insurance Agency</u>, in partnership with the Department of Social Services and the National Disability Supports Quality and Safeguards Commission, should require early intervention capacity building supports for children be based on best practice principles and evidence.
- 📑 Action 6.6: The <u>National Disability Insurance Agency</u> should develop and implement an approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children.
- Action 6.7: The <u>National Disability Insurance Agency</u> should implement reforms to support the continuum and pathway for children using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

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5.1. The NDIS is not part of a broader continuum of support for children and families

A lack of a coordinated approach across governments has meant there are significant gaps in the accessibility and availability of supports for children and families. We have heard many families have either had to go without support or seek access to the NDIS as a result of the limited support available outside of it. Many mainstream services also push children and families towards the NDIS.

A more joined-up approach across service systems and governments to meet the scale and diversity of need of children and their families is required. A more coordinated approach will help to create a continuum of supports that can respond to different types and levels of need. This will require a series of reforms across mainstream and foundational service systems and the NDIS. It requires governments to work together.

We proposed a spectrum of supports that are more responsive to different types and levels of need. The NDIS should be one part of this. This should be achieved through mainstream services having a more consistent approach to identifying need and inclusively supporting children with developmental concerns and disability, an increase in foundational supports outside the NDIS for children and families who have higher needs than mainstream supports can effectively respond to, and a best-practice approach in the NDIS to support children with developmental delay and disability and their families.

These reforms should be considered as a package with proposals for foundational supports and mainstream services. An abridged version has been included in this section to provide context on the changes required outside the NDIS to create a continuum of support. Additional detail is available in Chapter 1.

5.1.1.   There is not a joined up approach across governments or service systems

A lack of a coordinated approach across governments has meant that families have either had to fend alone without any support or seek access to the NDIS.

As a result children can miss out on supports during the unique period of rapid brain development that plays a critical role in shaping a person's life trajectory. This is an important window to improve long term outcomes. It also means that families are missing out on critical supports during the time they are learning about their child and how to best meet their needs.

> *"There is no 'joined up system'. All levels of government 'know' our son: he was born in a [state] hospital, he has been receiving health care and immunisations since birth, he attends a council-run preschool, he was diagnosed with autism in a [state] hospital, and now we are enrolling him with [state] schools - and yet EVERY SINGLE TIME we deal with one of these services, we start from scratch explaining his history, his needs, his diagnosis." – Carer* [779]

> *"Since the rollout of NDIS in the south west region, we are increasingly observing a siloed approach to support for children and youth with disability. This has the effect of families being pinged back and forth between mainstream services and the NDIS, unable to access the supports which are desperately needed." – South West Autism Network* [780]

> *"The main places that children live in are at home and in childhood services such as preschools and schools. These are now split between the Commonwealth NDIS and the State run early childhood and school services. In the introduction of the NDIS there was an agreement to work closely at the local level to plan coordinated streamlined services for individuals requiring both school education and disability services. The NDIS market model means there are no clear expectations about how NDIS funded services should interact with children's services or schools. Similarly, schools make their own decisions about coordination. The result is one of three interactions between the services: • no interaction • a service based on withdrawing the child from their*

activities • a level of cooperation. In the worst-case scenarios this has led to situations which are detrimental to a child's development, including a child who has one behaviour support program for school and a different one at home and a child who has one communication device at school and a different one at home." – Noah's Ark[781]

There are three main issues currently preventing a more coordinated approach to identifying and responding to need:

Mainstream systems: Child development systems are not consistently effective in identifying and inclusively supporting children with developmental concerns and disability.
Foundational system: There are few supports outside the NDIS for children and families who have different or higher needs than mainstream supports can reasonably or effectively respond to.
Specialist disability system: The NDIS has not been able to implement a best practice approach to supporting children with developmental delay and disability and their families.

Each of these issues is explored in further detail below.

Child development systems are not effective in identifying and inclusively supporting children with developmental concerns and disability

Identifying need

Children with emerging developmental concerns and disability need to be identified as early as possible to ensure timely support can be provided. Gaps in development open early and widen progressively without early intervention.[782]

"Early identification and intervention are crucial. Regular developmental screenings can help identify concerns early and allow for timely intervention." – Person with a disability and Carer [783]

"The most efficient way to support all developmentally vulnerable children is to identify them and commence supports within their first 1000 days... Regardless of where they live, all children should have access to a minimum number of maternal and child health (MCH) visits, where their development (social-emotional, language and physical development) and the primary caregiver's wellbeing are monitored throughout the first 3 years of life." – Olga Tennison Autism Research Centre [784]

Many children with developmental concerns and disability are not being identified as early as possible. This means their needs are not being met as soon as they should be and a critical window for intervention is lost. For example, while the average age of entry for children accessing the NDIS has improved, it still remains well past the critical 1,000 day period.[785] It should be noted that part of this timing is based on the speed of the NDIS access process following a developmental concern being identified.

Figure 53: Average age of entry for children aged under 9 entering the NDIS[786]
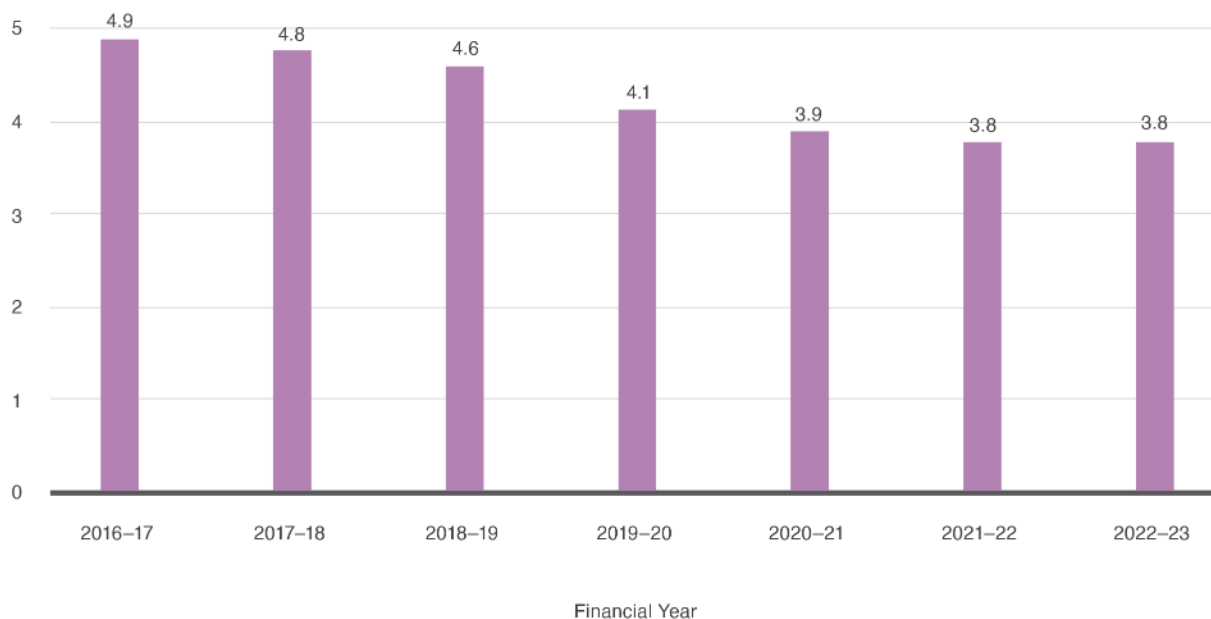
All states and territories have established maternal and child health services for conducting child health and development checks across the ages and stages in the early years. However, the frameworks and approaches for these checks varies across jurisdictions.[787] Figure 54 shows further detail on the frequency of recommended and offered child health and development checks across different jurisdictions.

In addition, some jurisdictions also have a high rate of drop outs from these services. This means the number of checks completed is far lower than what is available.[788]

There is also a lack of consistently reported data across jurisdictions on the uptake and usage of these health and development checks, as well as more targeted services.[789] This creates a significant gap in understanding the coverage and outcomes of developmental monitoring across Australia and how they link to early intervention services. It also means there is not enough data on need to better inform policy and program responses.

Figure 54: Child health and development checks by jurisdiction (note we have attempted to group checks together by timing to make comparison easier). Hv = hospital visit. Doc = doctor [790]

National	NSW	VIC	QLD	SA	WA	TAS	NT	ACT
Checks <12 months								
Birth (hv) 1-4 weeks	Birth (hv) 1-4 weeks	Birth (hv) 2 weeks 4 weeks	0-4 weeks	1-4 weeks (hv) 2 weeks (doc)	0-2 weeks	2 weeks 4 weeks	0-10 days (hv) 4 weeks	1-4 weeks
6-8 weeks	6-8 weeks	8 weeks	8 weeks	6 weeks (doc)	8 weeks	8 weeks	6-8 weeks	6-8 weeks

		4 months	4 months		4 months		4 months	4 months
6-9 months	6 months		6 months	6-9 months		6 months	6 months	6 months
		8 months					9 months	
Checks >12 months								
	12 months	12 months	12 months		12 months	12 months	12 months	12 months
18 months	18 months	18 months	18 months	18-24 months			18 months	18 months
2 years	2 years	2 years	2.5-3.5 years		2 years	2 years	2 years 2.5 years	2 years
3 years	3 years	3.5 years		3 years			3 years 3.5 years	3 years
4 years	4 years		4.5 years		4 years	4 years	4 years 4.5 years	4 years

Inclusive mainstream supports

All children benefit from high quality early childhood education and care. These outcomes can be multiplied for children with disability and include cognitive, language and social benefits as well as academic outcomes.[791] For children of school age, the academic impacts of inclusion have been studied widely across the world. Multiple systematic reviews found students with disability who were educated in general education classes academically outperformed their peers who had been educated in segregated settings.[792]

> *"We need all disabled children to receive the supports they need to attend mainstream schools. The more ordinary that becomes, the more inclusive society will become. When non-disabled children who have routinely studied alongside their disabled peers become the leaders and employers of society, disability inclusion will also be ordinary. Non-disabled people will have learned to expect it - just as most of today's leaders and employers have learned to expect the exclusion and segregation of disabled people." – Participant [793]*

However, there is evidence children with disability and developmental concerns are not consistently being included.[794] Children with disability and developmental concerns are not enrolled in preschool in line with their prevalence in community, can experience difficult transitions to school and can face barriers to accessing and maintaining enrolments.[795] Inclusion Australia describe decisions to enter segregated learning environments as the start of the 'polished pathway' where people with intellectual disability face significantly lower barriers to future segregated

environments in housing and employment.[796] An evaluation of the Inclusion Support Program found around one in five parents of a child with additional needs reported having to change childcare because of issues with care.[797] This is double the rate of parents without disability.

> *"Given the substantial proportion of children with disability or developmental delay, inclusion approaches must be core business in early learning." – Autism Queensland*[798]

Families told us of the fraught experience in transitioning to school and securing adjustments.[799] Families and students often need to meet complex criteria to receive disability support in schools and as a result some miss out. For example, children may need to meet a certain IQ threshold before receiving support and only some types of disability are being funded and supported.

> *"Allow for the provision of supports by physiotherapists in natural environments in a variety of settings – childcare, school, home, community, etc. Everywhere it is relevant to the child to improve access and participation." – Australian Physiotherapy Association* [800]

Children who are accepted into mainstream schools often experience discrimination because of their developmental concerns or disability. They often face suspensions and expulsions and restrictive practices at high levels.[801] The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) similarly heard about the lack of inclusion and adjustments[802] and found that 'Australian schools do not consistently deliver an inclusive education that protects students with disability from violence, abuse and neglect'.[803]

> *"The NDIS will only be able to achieve its full potential if children and young adults with disability get an education that adequately prepares them for later life." - Children and Young People with Disability Australia* [804]

There are few supports outside the NDIS for children and families who have different or higher needs than mainstream supports can reasonably respond to

Early Supports

There are a group of children with developmental concerns or disability who require different or a higher level of support than can be reasonably provided by mainstream services. At the same time, this need may not be so high that they require specialist supports in the NDIS.

Currently, some of these children are referred to Early Supports provided by NDIA Early Childhood Partners. These are intended to build capacity in both children and families. We have heard about a number of challenges with this existing Early Supports program. There is limited availability and service coverage to meet need as well as a lack of integration between the Early Supports and other mainstream services (such as education).

> *"Ensure all state and territory governments have the funding they require to provide the early support services, early therapeutic intervention (allied health services, not just playgroups and parenting courses) as part of the service system." – Carer* [805]

Early Childhood Partners do not provide coverage to all areas in Australia. As a result some communities are not able to access Early Supports at all. Where it is available, uptake remains relatively low. This suggests that families do not currently view it as a credible or effective way to support their child. Early Supports is a subset of Early Connections. There were less than 15,000 children younger than 7 accessing Early Connections as of June 2023.[806] By comparison, there were just under 100,000 children younger than 7 with an active NDIS plan as of June 2023.[807] This is more than six times as many accessing Early Connections.

The NDIA Early Childhood Early Intervention Reset Project (ECEI Reset Project) similarly found that the perception of Short Term Early Intervention (STEI) and Initial Supports (the former names for what is now Early Supports and Early Connections) needs to be improved among families and mainstream services. It also found that the perception of Early Support initiatives as a 'gateway' to the NDIS and an inferior support offering needed to be changed.[808]

Part of this challenge is the limited and capped level of support provided. Early Childhood Partners appear to be funded to deliver up to approximately 17 hours of support for each child.[809] This is a time-limited support for usually three to six months but can be up to a maximum of 12 months if required.[810] Critically, the 17 hours of support appears to be the maximum. The actual availability of the support and hours of delivery depends on the resourcing constraints of the Early Childhood Partner.

This is significantly less support than a child would receive in the NDIS even at the lowest end of plan values. The ECEI Reset Project noted a sizable difference between the 'average amount of money spent on the 10 per cent of young children receiving Early Supports ($2,000 per year), compared to the 90 per cent with an individual support budget ($17,900 per year).'[811] While these figures predate efforts by the NDIA to increase Early Childhood Partners capacity to deliver Early Supports, it highlights the large disparity in the level of support for those outside and those inside the NDIS.

> *"According to the recent tender, children with disability or developmental delay will be eligible for "early supports". They will receive a little more support - up to 17.2 hours per child, which is available over a maximum period of 12 months, but they will be limited to accessing these early supports only once and the NDIA estimates that only 4,200 children nationally will be eligible. Early supports are payable to the EC partner on a "part-variable payment" basis, meaning that actual provision of these services will be limited by the resourcing of the EC partner" – Healthy Trajectories Child and Youth Disability Research Hub [812]*

An added complication is that the delivery of Early Supports has been effectively situated inside the NDIS by using Early Childhood Partners to deliver the support. The practical impact of this decision is that supports are not being delivered in an integrated way in mainstream services and in the community.

Early childhood professionals and researchers are concerned that this has meant Early Childhood Partners have become part of the disability service system and are no longer closely connected to mainstream early childhood education and care, education, health and recreational services.[813]

We also heard about the significant gap in services for children in remote and very remote locations. This disproportionately impacts First Nations children. The ECEI Reset Project recommended that more tailored methods of delivering supports were needed in remote and very remote areas.[814] This highlighted the need for more place based and community partnership approaches to better respond to local circumstances. Despite the recommendation, we have heard that little has changed in these communities. Action is needed to address the inequity in access to Early Supports and NDIS early childhood supports.

<u>Support for families</u>

Most people have no experience of developmental concerns or disability until it occurs within their own families. It can be a highly overwhelming time. Families need to be empowered with information, advice and peer support from other families so they can build skills and confidence to support their child. Families must receive support in addition to support for their child because children thrive in well supported families.

Without the right information, advice and support families can become focused on seeking more and more therapy. It is understandable in the early period following a child's diagnosis and the family's journey to believe if a little bit of therapy is helpful, even more must be better. But an exclusive focus on therapy can come at a cost to the child and family's wellbeing and participation in their community. In some cases, the focus on therapy can extend to seeking a 'cure'. This reinforces a medical model (rather than a social model of disability) which can mean therapeutic supports are prioritised over support for the family as a whole.

Families of children with developmental concerns or disability experience additional stress and demands on their time. Additional support is critical to mitigating the isolation, exhaustion and stress that families and caregivers can experience. There are currently patchy approaches to supporting families early in their child's journey. There are some family capacity building organisations providing valuable support. They are, however, not widely available or even known. We have heard that families currently have limited access to capacity building and peer support despite the evidence of its impact and cost effectiveness. There is also limited access to neurodiversity affirming organisations that promote contemporary models of disability and positive visioning and inclusion. Research commissioned by Disability Advocacy Network Australia highlighted the importance of families receiving 'peer and professional support that orientates them towards inclusion.'[815]

> *"...empowered parents and carers positively influence needed social changes every day with individuals and within every environment and every service and system they engage with. Empowered parents and carers raise empowered children and young with disability and prepare them to participate in, and contribute to, social and economic life." - The Association for Children with Disability Tasmania* [816]

Funding for family capacity building services has been provided through grants as part of the Information, Linkages and Capacity Building (ILC) program. However, the ILC program has struggled to respond to the need of families of young children with developmental concerns and disability. There are a range of funded initiatives that aim to support families or parents and build their capacity through information, online communities, peer support and leadership. This means there are high-quality existing initiatives, but there is no approach to ensuring these are consistently available for families across Australia. The grant based approach has resulted a range of disparate projects that both overlap and leave gaps at the same time. The approach also relies on organisations to identify need, develop solutions and be successful through the grant round. This leaves far too much to chance when there is clear evidence of significant benefits from building the skills and confidence of families to support their child.

> *"On the ILC grants front, there is no strategic or overarching needs assessment, measurement of return on investment, or tracking of the impact of ILC grants on demand for NDIS funding. Evidence about the extent to which ILC is effective in improving outcomes for people with disability, or whether ILC is reducing demand for NDIS funding packages, is lacking." – Disability Advocacy Network Australia [817]*

Research commissioned by the Department of Social Services (DSS) similarly found the current peer support system to be fragmented and disconnected from other service systems.[818] It noted there were significant gaps around systems navigation support and support for families of children who may not have a diagnosis, are not part of the NDIS or who are waiting to access supports.

Information and navigation support

Research indicates that families need information, confidence and capacity to make informed decisions.[819] Yet we have heard that families are 'cobbling together information about the best way forward.'[820] We also heard about how the NDIS has inadvertently 'over-developed the specialised support laneway' to the detriment of community inclusion and parent-peer led approaches.[821] Families are having to fill in information gaps themselves and pick up the additional workload of navigating different supports and programs for their children.

> *"I reflect on the four years that I lost. Four years of not seeing qualities that my daughter always had that were invisible to me, yet in plain sight." – Plumtree Children's Services [822]*

The NDIS has not been able to implement a best practice approach to supporting children with developmental delay and disability and their families

Children with higher needs require specialist disability supports from the NDIS. Children younger than 6 with developmental delay or children younger than 9 with disability and their families are currently supported through the NDIS early childhood approach.

Development of the early childhood approach was informed by evidence-based research. It is intended to 'support best practice in early childhood intervention because it helps the child and

family to build their capacity and supports greater inclusion in community and every day settings.'[823]

A number of previous reviews have identified problems with the way the approach was implemented for children.[824] The ECEI Reset Project found that a reset was required to ensure it delivered on its strategic intent of ensuring children benefit from early intervention supports and families can identify and receive best practice supports (see box 31 below for an overview of key areas for improvement from the ECEI Reset Project).[825]

Box 31: Areas for improvement identified in the ECEI Reset Project[826]

The NDIA launched the ECEI Reset Project in May 2020 to address the challenges and implement the recommendations identified in the Tune Review of the NDIS Act (December 2019) and Independent Advisory Council report on Promoting best practice in early childhood early intervention (March 2020).

Those reviews highlighted challenges in the implementation of the early childhood approach and made recommendations to help it fully achieve its strategic intent. This included providing timely support to children, improving functional outcomes, building skills and confidence in young children and their families.

The objectives of the reset were to:

- Improve outcomes for young children and their families/carers
- Enable the right children to receive the right supports at the right time
- Develop short and long term solutions for identified pain points, challenges and gaps.

The ECEI Reset Project made 23 recommendations to address nine key areas of improvement.

The nine areas are set out below:

1. The early childhood approach needs to reconnect with and better communicate the original clear vision, and should be adequately differentiated from the rest of the NDIS
2. There needs to be a more clearly articulated NDIA position on what constitutes best practice in early childhood intervention
3. The NDIA needs improved decision making processes and tools to enable more consistent, fair and equitable decision making around access and planning
4. Children and families need to be more consistently supported through the right pathway
5. Children and families need to receive more consistent support at the right time
6. Children and families need to be more consistently receiving the right level of supports
7. Children and families should be offered greater assistance to understand and select a best-practice mix of supports

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> 8. Young children and families that are vulnerable or disadvantaged are currently under represented and need to receive equity in plan budgets and engagement with supports
> 9. More children should be achieving the desired outcomes and successfully transitioning to the next phase of their life which may or may not require NDIS funded supports.

Despite the work of the ECEI Reset Project we have heard many of the same issues remain. Best practice is still not embedded, access to the NDIS is not always needs-based, planning is complex and traumatising for many, and there is not appropriate monitoring of children's progress in the NDIS.

A brief summary of these issues is provided below. Greater detail is provided in Sections 5.2-5.5.

- Embedding best practice: Best practice is still not embedded in NDIA processes or NDIS service delivery. Efforts to encourage families and the market towards best practice supports and service models have not been effective. This is despite the early childhood approach being established in line with the best practice principles.[827]
- Accessing the NDIS: Access to the NDIS is not always based on need and as a result is inequitable. Developmental delay is one of the main ways young children enter the NDIS. There is however still significant uncertainty in how the NDIS determines whether a child has substantial delay or substantially reduced functional capacity. There is no clear definition or consistent approach to determining this. While the use of Access Lists has made entry into the scheme simple and straightforward for some, outcomes have been inequitable, particularly for those who do not have a diagnosis. Children with the same level of support need but different diagnoses can get different outcomes.
- Planning: Planning processes are complex and traumatising. Families feel unsupported during the planning process. They feel compelled to 'paint' their children and their needs in the worst possible light in order to access support. Funding outcomes are highly dependent on evidence presented and the advocacy skills of parents. This is traumatising for many families.
- Monitoring progress and outcomes: Children's progress is not monitored and outcomes are not being evaluated. There are few mechanisms to monitor children's development, functioning and progress towards goals and outcomes in a safe, non-judgemental and responsive way. It is currently heavily linked to re-assessments and planning processes which are not suitable for this purpose. There is not any feedback loop to drive change in approach or learn from success.

5.1.2. A continuum of support is needed to better cater to different levels and types of need

Far more support should be available where children live, visit, learn and play to reduce the pressure on families to access the NDIS for support. Implementing a holistic and joined up

continuum of supports for children with disability and developmental concerns should be an urgent priority for all governments.

Children with developmental concerns and disability should be matched with supports that best meet their needs. This requires improved availability, accessibility and inclusiveness of mainstream and foundational supports. This would create a continuum of supports, matched to the needs of children and their families, and also relieve pressure on families to access the NDIS for support. Figure 55 provides an illustration of this continuum.

Children with higher support needs should be able to access the NDIS through a more consistent and robust access process. Children who are eligible for the NDIS should receive a budget based on support needs, determined through child-specific assessments.

All early intervention supports for children, including those provided through the NDIS and foundational supports, should be evidence informed and based on principles and evidence of what works. Providers who deliver capacity building supports in the early childhood approach should be required to be registered to increase the uptake of best practice services. This should be complemented by a consistent approach to ongoing monitoring and evaluation of the effectiveness of early intervention for children.

Government is approaching a critical point for transformative change for children and families. Findings and recommendations will soon be available from the Early Years Strategy, National Autism Strategy, National School Reform Agreement, and Productivity Commission inquiry into the early childhood education and care sector.[828] These provide an opportunity for governments to strengthen the support available to children and families through mainstream and foundational service systems.

Figure 55: Overview of the future continuum of support for children and families

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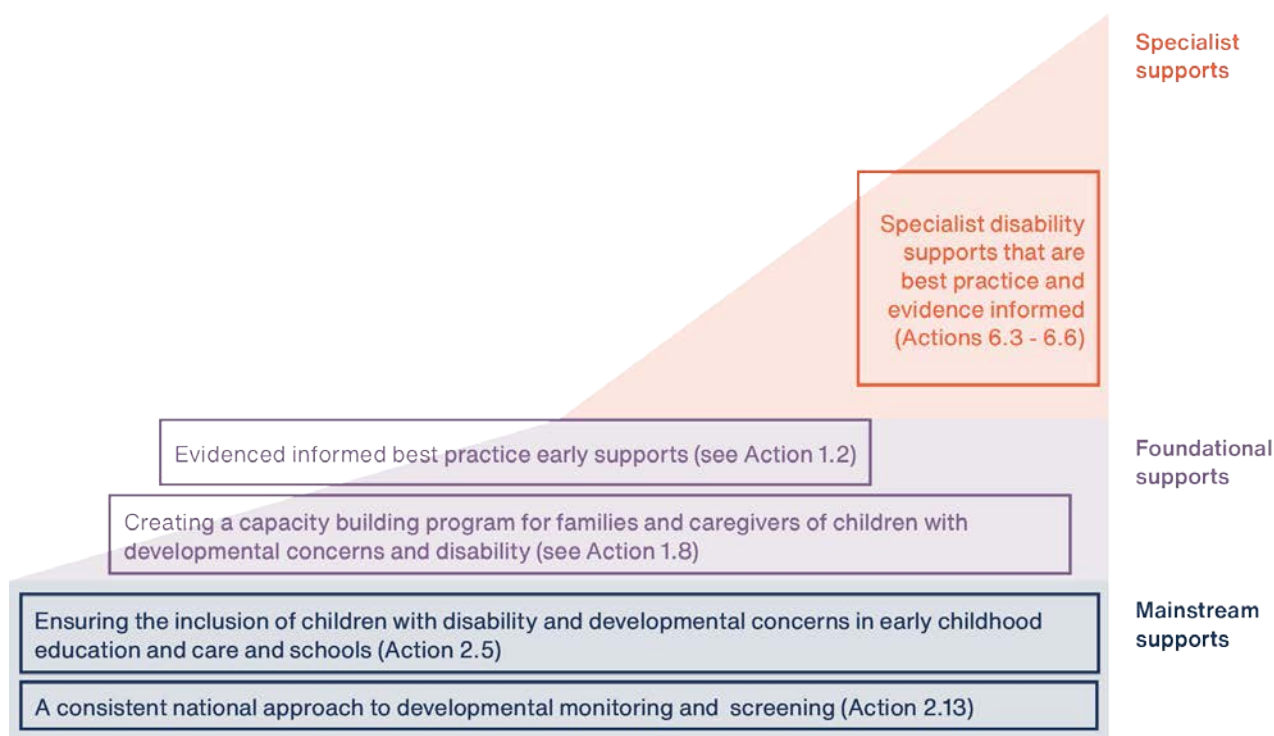
This should be achieved through the following actions. These proposed actions have been summarised below and are covered in detail in Chapter 1.

Mainstream systems: a more consistent approach to identifying need and inclusively supporting children with developmental concerns and disability

Identifying need

There should be consistent early identification of developmental concerns and disability that enables timely responses to need. This would be delivered through an expansion of universally available child development checks. The expansion should include a consistent minimum level of developmental monitoring over children's ages and stages, to ensure the early identification of children with developmental concerns and disability and enable timely early intervention (see Action 2.13).

Inclusive mainstream supports

Early childhood education and care and schools should be more inclusive and allow children to fully participate in education with their peers. This would be delivered through additional steps to protect the right to inclusive education for children with disability and developmental concerns in early childhood education and care and schools (see Action 2.5).

Foundational system: Far more support available outside the NDIS for children and families who have different or higher needs than mainstream supports can reasonably respond to

<u>Early supports</u>

There should be support available to help children to build their skills and participate in everyday activities. Support should also build the confidence and knowledge of families to support their child in everyday routines. Supporting children through normal daily routines ensures children develop and practice their skills in the settings in which they will be used rather than in clinical settings. Families need support to find ways to embed skill development in everyday routines so therapy activities and tasks do not add to family workload and stress.

These supports should be delivered through expanding the investments in early supports for children with emerging developmental concerns and disability and their families (see Action 1.12). These supports must be consistent with best practice and be informed by contemporary evidence of what is effective. Organisations that are approved to provide Lead Practitioner supports in the NDIS may be well placed to deliver these supports (see Section 5.2.7 for an introduction to the concept of a Lead Practitioner and their role in the early childhood approach). This is because Lead Practitioners are required to have expertise in child development to be able to support families in an evidence informed, principles based way.

Lead Practitioners should be a qualified allied health practitioner, developmental educator or early childhood educator who is trained in an approach based on best practice principles. In practice, this may mean the Lead Practitioner is responsible for leading group sessions or workshops or working directly with the child and family. This will reflect the need of the child and the family. The delivery of these early supports should be closely linked to and integrated with mainstream services, particularly education and early childhood services.

<u>Support for families</u>

Families should be empowered with information and resources and connected with other families so they can build skills and confidence to support their child. This should be delivered through an expanded capacity building program for families and caregivers of children with developmental concerns and disability (see Action 1.8).

<u>Information and navigation support</u>

Families should also have support from a locally connected Navigator. Navigators would provide information, advice and help families find and access supports across mainstream and foundational systems and the NDIS. This would be delivered by the commissioning of a navigation function to help families of children with disability and developmental concerns find supports in their community and make the best use of their child's NDIS funding (see Action 4.1).

Specialist disability system: A best practice approach in the NDIS to support children with developmental delay and disability and their families.

<u>Embedding best practice</u>

There must be a greater focus on embedding best practice within the NDIS. Families should be guided and supported towards evidence-based services delivered by providers experienced in best

practice. This would be delivered by reforming the pathway for all children under the age of 9 to enter the NDIS under the early intervention requirements (see Action 6.2). There would also be dedicated support for the child and family from a Lead Practitioner to help coordinate supports and ensure this workload no longer falls to already stretched families (see Action 6.5). This is in addition to the general support also available to all people with disability and their families from a Navigator.

Early intervention supports for children should also be based on best practice principles and contemporary evidence of what works (see Action 6.5). Providers delivering supports to children would be registered, consistent with the graduated risk-proportionate regulatory model for all NDIS supports (see Action 17.1) and supported by strengthened Early Childhood Practice Standards that are aligned with the best practice principles.

Access to the NDIS

There should be greater clarity on who the NDIS is for and what evidence is needed to support an access request. There should be a more consistent and robust approach to assessing developmental delay (see Action 6.3) and clarifying the definition of the key criteria for accessing early intervention supports, including what 'likely to benefit' in section 25 of the NDIS Act means (see Action 6.2).

Budget setting

There should be a more strengths-based approach to determine the supports needs of a child. This will be delivered by setting a budget at a whole-of-person level, and introducing a new needs assessment process to more consistently determine the level of need for each child and linking this to the budget (see Action 6.4).

Monitoring progress and evaluating outcomes

Greater mechanisms are needed to monitor how a child and family are responding to early intervention supports. There should be multiple ways to monitor progress and measure any changes in the child development, functioning or progress towards outcomes. This would be delivered by a new approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children (see Action 6.6).

5.1.3. Action & Implementation Details

Action 6.1: National Cabinet should agree to jointly invest in a continuum of mainstream, foundational and specialist supports to address the needs of all children with disability and developmental concerns.

Supports provided outside the NDIS should include mainstream supports (including early identification of children with developmental concerns and inclusive education, see Actions 2.5 and 2.13) and foundational supports (including expanded supports for children with emerging developmental concerns and disability and programs, see Action 1.12). Within the

NDIS, children under the age of 9 with higher levels of need should receive specialist support through a reformed early intervention pathway (see Action 6.2).

Implementation detail:

- The Department of Social Services should ensure children with disability and developmental concerns are a key priority in all intergovernmental agreements and strategies to ensure coordinated and joined up efforts to improve outcomes for children.
- Australian governments should take immediate actions to establish a more coordinated and joined up approach to improving outcomes for children through the establishment of a continuum of supports, including:

  - Mainstream supports: Early identification of developmental concerns and disability through developmental monitoring and screening to ensure need is identified early (see Action 2.13) as well as greater inclusion of children with developmental concerns and disability in early childhood education and care and schools (see Action 2.5).

  - Foundational supports: Greater investment in capacity building programs for families and caregivers of children with developmental concerns and disability (see Action 1.8) as well as additional funding for programs to deliver best practice early supports for children with emerging developmental concerns and disability (see Action 1.12).

  - Specialist supports: A reformed NDIS early intervention pathway for children under 9 (see Action 6.1). With a rigorous focus on the delivery of best practice early intervention supports (see Action 6.5).

Note: Action 6.7 applies to all reforms across the continuum and NDIS pathway. It has been included earlier in the chapter for this reason. It applies to all proposed changes to the pathway.

Action 6.7: The National Disability Insurance Agency should implement reforms to support the continuum and pathway for children using an iterative, inclusive approach to design and testing, and ensure participants experience a smooth transition to the new arrangements.

Reforms to the pathway for children (see Action 6.1 to 6.6) should be designed through agile projects commissioned by the NDIS Experience Design Office (see Action 24.3). Design, testing and implementation should be undertaken in consultation with families of children with disability or developmental delay, and should build on the principles and implementation considerations set out in the Co-Group Feedback to the NDIS Review Panel, developed as part of the Review's participatory engagement process (for further details on

the Co-Group's work see <u>Appendix B</u>), as well as the Australian Government Digital Service Standard.

Inclusive and proportional user testing should be conducted to allow priority reforms to be phased in and start delivering benefits as soon as they are validated and approved by Disability Reform Ministers for implementation. The assessment processes in particular require highly transparent, rigorous and inclusive design and testing prior to implementation.

The implementation of the changes to the pathway would adhere to a principle that ensures all current participants experience a smooth and fair transition to the new arrangements (see Action 26.2). Implementation of this recommendation should be consistent with broader reforms to the participant pathway (see Recommendation 3), and should be directly linked to implementation and ramp-up in foundational supports for children under the age of 9 and their families (see Actions 1.8 and 1.12).

Implementation detail:

- The Australian Government should ensure the NDIS Experience Design Office is appropriately resourced and funded to attract appropriate expertise and experience to deliver on its scope of work, including but not limited to:

  - Capability to deliver an extensive program of iterative design and testing, including expertise in agile delivery, experience design, prototyping and product development, service design, user research, business analysis, commissioning and service delivery.

  - Significant lived experience representation within teams, management and the executive.

  - Technical expertise in developmental assessments, needs assessments, measurement, child development and the delivery of best practice early intervention supports for children. This should include individuals with frontline assessment experience and delivery of best practice supports for children.

- Once the NDIS Experience Design Office has been established, reforms to the participant pathway should be designed with consideration of the following:

  - The assessments should be reviewed through a transparent process that involves extensive testing of existing validated instruments and any subsequently modified or developed assessments and processes. The design process must include (but not be limited to) families of children with disability or developmental delay, developmental measurement experts, health professionals, child development experts and representative organisations.

  - It is envisaged the needs assessment (see Action 6.4) could be first implemented as an information gathering process within the existing planning pathway (without it being directly linked to budget setting). This would provide for a smoother transition between the current pathway and the proposed future pathway. It would also allow

for wider testing of the assessment and building broader familiarity with the assessment before the new approach to budget setting is introduced.

- When pathway reforms are being implemented, the National Disability Insurance Agency should ensure that all participants receive a smooth transition to the arrangements. This includes any participants who experience a change to their funding arrangements during their first needs assessment.

5.2. Families will continue to be let down without stronger efforts to embed best practice principles across the continuum of supports

The central goal of early intervention supports should be to promote the capacity of the family to support their child's learning as part of everyday routines and to ensure the inclusion of children in mainstream settings with their peers. This is both rights-based and best practice.[829] Supports funded by government must be underpinned by a best practice approach. This is important to maximise long-term outcomes for children and families, as well as for the social license of the NDIS as a taxpayer funded scheme.

Efforts over the last ten years to encourage families and the market towards a best practice approach of delivering early intervention supports have failed. There has been limited attention paid to informing and building the capacity of families and caregivers. Planning processes and therapy responses remain highly child-focussed. This is not consistent with best practice that centres and supports families. There has also been a proliferation of clinic-based therapy rather than supports delivered in natural settings such as homes, preschools and community groups. This is not leading to good outcomes for children or families.

We propose a new approach that requires early intervention capacity building supports for children be based on best practice principles and contemporary evidence of what works. This should be achieved by better supporting families to demand best practice supports and requiring providers to supply best practice supports. There is also an immediate need to reach agreement on evidence based interventions and deliver a contemporary best-practice framework that can be applied consistently across government funded supports in Australia.

5.2.1. Best practice is about taking a family centred and inclusive approach

The NDIS early childhood approach was developed based on evidence-based research with the help of leading experts in early childhood intervention. The early childhood approach is intended to support best practice in early childhood intervention by helping the child and family to build their capacity and support greater inclusion in community and every day settings.[830]

Best practice refers to core principles that guide how early childhood practitioners work with families of children with developmental delay and disability (these principles are illustrated in Figure 56). At its core, best practice is about taking a family centred and inclusive approach.[831]

Family centred means planning, supports and outcomes consider the holistic needs of the family, including the child with disability or developmental delay, parents, caregivers and siblings. Well supported families lead to well supported children.

Taking a best practice approach to supporting families is critical to improving outcomes for children and families. Evidence shows that 'Children learn most in the environments in which they spend most of their time, and not in specialist intervention sessions: what happens between formal sessions is when the majority of learning takes place, and not in therapy sessions: children learn from their natural caregivers, whether we want them to or not.'[832]

Figure 56: Illustration of the best practice principles[833]

Further detail on what these best practice principles mean is provided in Figure 57 below.

Figure 57: Overview of the key best practice principles (adapted and sourced from Early Childhood Early Intervention Victoria / Tasmania resources)[834]

Principle	Summarised description	What does this mean in practice?
Family-centred and strengths based	The role and expertise of family is respected. Working in an equal and active partnership helps build on what families are doing well and deliver on family priorities. Information and knowledge empowers families.	*'I felt that I could talk to our key worker about what I wanted for my child and that I was really heard when it came to setting up goals. Because I had so much input the goals were real strategies that we could do as a family in our everyday life.'[835]*
Engaging the child in natural environments	Children develop through play, routines and experiences where they live, play and learn.	*'Jasmin's language skills just came in leaps and bounds when she started kindergarten. I think it was because she was around other children all day doing real things that she enjoyed doing and was supported by her teachers and key worker. Kindergarten is now a big part of her life and our weekly routine.'[836]*
Collaborative teamwork	Family, practitioners and others work together as a team around the child (coordinated by a key worker).	*'My head spins when I think of all the different services Ashley was involved in and all the appointments we went to. I just couldn't keep up with it all, let alone try to keep everyone in the loop. That was until Ashley's key worker came on board. She knew about local services and coordinated the team so it really worked for Ashley and us. We benefited from the combined knowledge and skills shared by the team so we felt more able to support Ashley's development without all the stress of finding what we needed. We are so grateful to our team and key worker.'[837]*
Capacity building	Learning and development is maximised by building the skills and knowledge of people who spend the most time with the child.	*'I knew how to play with my child, but didn't realise how play could be therapy too, until I was shown. Now when I play with Sophie I include some fine motor skills that are fun and meaningful. I feel so confident in what I am doing and have really seen progress. I have shown Sophie's educator what to do and how to include it in child care in a fun way. Now I feel like the coach.'[838]*
Culturally responsive	Diversity is respected and supports are tailored for different cultural, language and social backgrounds, or different values and beliefs.	*'We don't have the words in our language to describe my son's disability so it was very important to us to have information. Our key worker organised an interpreter and some information was translated into our language so we understood what we could do for our son.'[839]*
Inclusive and participatory practice	Children are fully included and able to participate in home and community life, with additional support as needed.	*'I was very worried when Arjun started childcare. Would he be looked after? Would the other children play with him? Our key worker supported Arjun in child care and worked with his educators to make sure that he could take part in activities and routines. To our surprise Arjun settled into child care well and has made some friends already. We are so happy for him.'[840]*
Evidence based and accountable	Practitioners are qualified and use evidence based approaches.	*'Interventions that are based on scientifically validated and reliable evidence are the ones most likely to work, be worth the time and energy you invest in it and be safe for your child.'[841]*
Outcomes based approach	Practitioners share knowledge and expertise to work towards outcomes based on family priorities.	*'As well as helping Donnie to talk and socialise, what we really wanted as a family was for Donnie to sleep through the night so we could function better as a family. Our key worker helped us work out ways of doing this while understanding what we could take on at the time.'[842]*

5.2.2. Despite having Best Practice Guidelines, best practice is not embedded in the NDIS

The Australian Government commissioned the development of Best Practice Guidelines for Early Childhood Intervention in 2015. This was in recognition of the need to establish clear guidance about what constitutes best practice in early childhood intervention. The guidelines are intended to help professionals work in a way that supports the best outcomes for children with developmental delay or disability.[843]

The principles outlined in the guidelines have ostensibly been used to develop the early childhood approach under the NDIS.[844] However, we have heard and seen there remains a significant guideline-to-practice gap within the NDIA's internal operations as well as within the NDIS market. The result is that children are not receiving the best supports despite the significant investment of funding. Australian children with disability and their families deserve much better.

Efforts to encourage families and the market to adopt a best practice approach have failed.[845] This is despite the NDIS early childhood approach being established using the best practice principles described above. The inability of the NDIS to effectively inform, support and build the capacity of families has been repeatedly highlighted. In 2020, the Independent Advisory Council to the NDIS stated "Recent evidence reviews reaffirm the efficacy of family-centred practice for children with all disability types, including children with ASD, but family-centred practice in the NDIS is undermined by the lack of attention to supporting families and building their capacity."[846]

Some of these challenges predate the NDIS. Before the transition to the NDIS, early childhood services based on best practice and family-centred practice were not consistently available across Australia. Individualised funding models that came before the NDIS contributed to a shift in practice towards more child-focused or clinical therapy service models, including Helping Children with Autism (HCWA) and Better Start for Children with Disabilities (Better Start). These rationed funding models incentivised families to select delivery of supports in clinical settings over natural settings to maximise face to face time with therapists.[847] The NDIS super-charged this trend.

We have heard the NDIS has contributed to a focus on the child as distinct from the family which has resulted in less support for families and disjointed services delivered by multiple providers. In a review completed for the Victorian Department of Education and Training, NDIS supports for children were characterised as being frequently "child-focused, therapy-driven, and disability framed".[848] We have heard the same. Submissions to this Review and feedback in engagement sessions has raised the increased focus on clinical-based therapy and lack of focus on families as a key issue in the NDIS:

> *"...We are dealing with two disabled parents but one is not on the NDIS... So what I've got is one that says my informal supports can help me and I have two plans for two children who have got parental responsibility for cleaning and cooking and all the rest. I am sorry, but who is this magical person who is doing this informal support because it's not me or my kids because we don't have the capacity to fulfil those requirements, so nobody has looked at this holistically and saying this is a family with these needs."*
> *– Anonymous [849]*

"The NDIS has the power to break families - it causes increased stress and anxiety and it can leave families feeling isolated and vulnerable. We are so busy supporting our child/person that requires care, that we don't have the opportunity to live our lives." – Inclusion Australia [850]

"There's very little support for parents with disability. We're still seeing the removal of children on the basis of the parent being disabled rather than providing the parent support." – Disability Advocacy Network Australia [851]

Providers, working as collaborative team around the family, is a key element of a best practice approach. However, the NDIS has contributed to a fragmentation of supports. Professionals are working individually with children in clinical settings with little collaboration or coordination with other professionals or providers. Individualised funding means there is no funding for anyone to coordinate individual therapists or create a team around the family. This falls on families or happens in a piecemeal way between providers.

"There is a lack of joined up working, collaboration of professionals and an overall sense that people work in silos rather than teams, this inevitably impacts upon the client." – Provider [852]

"Positive outcomes for children with disability and those with emerging developmental concerns are more likely to be achieved when all ECI professionals working with the child and family collaborate with the family and each other." – Special Teaching and Research Ltd [853]

The NDIS has also led to significant growth in the demand for therapy supports. Allied health professionals have limited availability and many children and families are stuck on waiting lists. Families have to choose based on who is available rather than having any real choice over the provider or the service model. The shortage of supports creates a strong incentive for therapists to deliver supports in a clinical setting as it increases utilisation of staff and reduces travel time. This means they can both support more clients (who otherwise would have missed out) and be more financially viable.

These issues are well known to government. The overarching intention of the ECEI Reset Project was to reset the implementation of the early childhood approach to achieve its strategic intent. It aimed to 'create a distinct ECEI implementation model… which enables the right young children to receive the right level and mix of support for the right period of time (including more pre-access assistance and transition support) through a family centred approach aligned with best practice'.[854] However, the NDIA has not had all of the levers available it has needed to deliver on this ambition, as it requires a simultaneous legislative, policy, and mainstream and foundational service system response. The changes required to fully implement the recommendations haven't occurred.

"The most recent changes to early intervention in the NDIS (with the move to the Early Childhood Approach) are creating more uncertainty, with few tangible signs that the

model is moving closer towards best practice." - Healthy Trajectories Child and Youth Disability Research Hub [855]

Despite all the challenges, we also heard about the strong positive benefits of family centred practice where it had been implemented. The case study below is the experience of a family with a keyworker that was organised by the hospital social worker.

A key worker is an early childhood professional who works alongside the family to support the child and helps coordinate a team of early childhood therapists and professionals. Key workers practice from a family-centred approach, supporting and empowering families. We use the term Lead Practitioner to refer to key workers throughout this report and in the proposed approach.

> **Case study 11: Key worker experience | Miley and her family supported by Sue (physiotherapist)**
>
> *This experience has been de-identified and uses fictional names.*
>
> In the beginning, we had a key worker, Sue, who was a physiotherapist who visited us fortnightly. I think she originally wanted to come weekly, but it would have been too much for us. Sue came with exercises for not only Miley (our child), but she also checked in on her health and the mental health of the family more broadly.
>
> Sue introduced us to the world of disability in a gradual way. From the outset, she reassured us that Miley would be supported throughout her life. Sue told us that Miley had the right to attend school and told us stories about some of the other kids that she had worked with and kept in contact with. She also told us about their successes in education, work and relationships.
>
> Sue didn't overload us with lots of information in the first session, but gradually spaced out the information over a year and made sure we were ready for the information before providing it.
>
> Sue also shared information about carer's allowance, the disability support pension for later in life and support available for Miley and our family. She also linked us in with the peak body advocating for Miley's disability and encouraged me to network with other families whose children had the same or other disabilities.
>
> After a few months, Sue started holding a group movement class to allow the kids and families to socialise. Lots of kids were isolated because of health and immunity issues or were busy with medical appointments or therapy so didn't get a chance to get out much.
>
> Sue also continued to keep up-to-date with our medical appointments and other challenges like sitting or feeding. She made suggestions about who we might need to see, like an orthodontist, audiologist or ophthalmologist.
>
> I was just lucky. A lot of families don't have this experience. It was tough being a parent of a newly diagnosed child juggling other children at home, having to breastfeed, pump and go back and forth between the hospital.

> If other families can get timely access to this type of support, it would be hugely helpful. I didn't even have time to apply for funding until Miley was a year old.[856]

5.2.3. Outcomes could be further improved with a focus on family-centred support to help children with disability and developmental delay and their families live ordinary, included lives

The NDIS has changed the lives of thousands of children with developmental delay and disability and their families for the better. There are many significant positive benefits being realised by children and families. However, it could and should be doing more.

NDIS outcomes data suggests there are negative impacts being felt from the child-focused, therapy-driven, and disability framed approach that has become ingrained in the NDIS.

This is particularly the case for inclusion in typical childhood experiences such as spending time on the weekend or after school with friends, playing sport or joining in other community activities or participating in a school holiday program.

What is clear is that the level of specialist services has increased significantly for children.

> *"I think there is still an expectation out in the community that if your child has a disability, that you are eligible for the NDIS and the NDIS alone. We call it the NDIA vortex because it has sucked everything up, and it's created this system where instead of being inclusive, we have children that attend exclusive playgroups where they are only around children with disabilities. They're not around their typically developing peers or their neurotypical peers. It is beyond sad for us because those children deserve to be around other children, and other children deserve to be around them. So, we find that because of this tale that's out there in the community, if your child does have a disability, you expect, well, you will get a fancy playgroup that is specific for children with autism or CP [cerebral palsy] or whatever. You get specific something, and the NDIS will take care of everything." – Anonymous [857]*

> *"These traditional approaches are drastically lacking in supporting individuals with developmental disability to genuinely participate in their communities. We note the expansion of the therapy sector such as Art therapy, Music therapy, Horse therapy to name a few. What was once an ordinary valued activity is now a form of therapy. Consequently, this takes people away from what should be valued and ordinary life experiences that could be otherwise shared with community members without a disability." – National Alliance of Capacity Building Organisations [858]*

> *"Children are often removed from the classroom for individual therapy (on campus) rather than supports being provided by therapists in the classroom or playground. This is often misrepresented as delivering support in the child's natural environment." – Australian Advisory Board on Autism [859]*

Best practice means that supports should be family-centred and there should be a 'focus on participation in meaningful activities in the home and community'.[860] However, outcomes data suggests this is not always occurring (see table below for more detail).

In particular, there has been reduction in the number of families who are able to socialise, ask others for help and see friends as much as they want to.[861] This suggests that families are still not getting enough family-centred support to help them live ordinary, included lives.

Just as importantly, there has also been a reduction in the number of children participating in mainstream classes and in after-school or outside of school activities.[862] Again, this suggests that children are still struggling to be included alongside their peers despite having significantly more support available.

Box 32: A sample of outcomes metrics where children and families are not seeing improvements (note that data is for children aged 0-14 and for families and carers)[863]

- 39 per cent of families have friends they can see as often as they'd like at the five year review – compared to 44 per cent at scheme entry (a reduction of 5 per cent).
- 32 per cent of families have people they can ask for practical help as they need at the five year review – compared to 40 per cent at scheme entry (a reduction of 8 per cent).
- 19 per cent of families are able to engage in social interactions and community life as much as they want at the five year review – compared to 28 per cent at scheme entry (a decrease of 9 per cent). Importantly, 97 per cent of those unable to engage as much as they like say the situation with their child is a barrier to engaging more.
- 37 per cent of children attend or have attended school in a mainstream class at their five year review – compared to 44 per cent at scheme entry (a reduction of 7 per cent of children). Noting that participation is generally higher for younger children and decreases as they age.
- 31 per cent of children participated in activities after school or on weekends with friends and/or in mainstream programs at their five year review – compared to 34 per cent at scheme entry (a reduction of 3 per cent).

5.2.4. There are a range of barriers preventing best practice being embedded in the NDIS

There are a range of barriers that have prevented wider implementation of best practice in the NDIS. This includes contested views about what exactly constitutes best practice.

The failure to achieve and operationalise a consensus on best practice has played out in how supports are delivered to children in the NDIS as well as in decisions about what constitutes reasonable and necessary supports for children.

The latter has resulted in applications to the Administrative Appeals Tribunal (AAT) where alternative service models that are starkly different and both argued to be based on evidence of best practice have been weighed against each other. There is still uncertainty about what exactly is

reasonable and necessary for children in this situation, particularly where more intensive or more costly support is requested.

There is also an inherent tension in balancing best practice and family choice. A family may choose an approach that is arguably inconsistent with best practice, or potentially even the rights of the child, but best practice itself centres family choices and recognises the expertise of the family. This creates a clear tension point.

Contest of best practice

One of the most significant challenges is the level of consensus about what constitutes best practice and the strength of evidence that underpins different approaches.

This includes early childhood developmental research, as well as evidence for specific disabilities, such as autism and cerebral palsy. While there are many similarities across the evidence, there are also key areas of difference and contest. These predominantly centre on whether an early childhood intervention:

- Has sufficient evidence to indicate it is likely to deliver meaningful benefits or outcomes for the child and their family.
- Is demonstrably safe to the child and avoids the risk of harm.
- Is cost-effective when weighing potential benefits and costs (a level of cost-effectiveness that government is willing to fund).

Notably, the Independent Advisory Council recently found in 2020 there was 'significant similarity' and some 'tension' identified between the Australian National Guidelines for Best Practice in Early Childhood Intervention and the Australian practice guidance for autistic children.[864]

The Independent Advisory Council summarised the significant similarities as '…with nuanced variations, both sets of practice guides agree on the importance of family-centre practice that is culturally appropriate, strengths-based, capacity building and outcomes-focused and delivered via a collaborative team approach'. Tension between the guidelines was identified in 'the individualised nature and weight given to skilled implementation of a carefully planned program that weakens the priority given to parents as partners and to inclusion in natural environments'. The Independent Advisory Council recommended the development of 'new practice guidelines for children with ASD to support best practice in ways that are sustainable for the NDIS'.[865]

In the same year, the ECEI Reset Project made similar findings. The project highlighted the 'widespread inconsistency in the interpretation and application of evidence to inform planning decisions for children with ASD and other disability types requesting an intensive level of supports such as Applied Behaviour Analysis'.[866] Recommendation 18 of the project was to 'publish new guidance about what is considered reasonable and necessary when making decisions for children on the autism spectrum based on evidence found in the Autism Cooperative Research Centre (CRC) 2020 report'.[867]

Subsequently, the Autism CRC released the Supporting Autistic Children Guideline following deep consultation with more than 1,000 Australians.[868] The guideline states that practitioners should

'inform parents that there is no set number of hours per week of practitioner delivered child-directed supports that leads to the best outcomes for all children' and that there is 'no one way to support all aspects of learning, participation and wellbeing for all children'.[869] By extension, there is flexibility in practitioners and families collaboratively determining who should deliver supports and where supports would be best delivered.

These three reports illustrate the level of contest about what constitutes best practice for different children and the role of the family in choosing a particular service model or approach. While this remains unresolved there will continue to be conflict between some families and the NDIA about the amount and type of service to be funded. It will continue to create tension between providers and families on the one side and the NDIA and government on the other. The peak of this tension results in escalation to legal challenges that are stressful and traumatic for families and costly for government to resolve.

Action by DSS to complete Action 2.4 of the ADS Early Childhood Targeted Action Plan to review the national guidance for best practice early intervention should go some of the way in resolving ongoing conflict.[870] We note however that work does not appear to be progressing with sufficient urgency and will soon be overdue.

Amongst the early childhood experts who engaged with the Review there was a strong view that the provision of family-centred practice and a key worker is consistent with the best practice principles. They suggested that the ongoing failure to make sure delivery is aligned with best practice principles has resulted in poor outcomes for children with disability and developmental delay and their families. The Review agrees that reform of the early childhood approach under the NDIS is urgent. While completion of the Early Childhood Targeted Action Plan is important, further reform should not be delayed while this work is done.

Willingness of government to fund best practice

Government should be satisfied of all three essential criteria are met before it is willing to provide funding for an intervention:

- There must be sufficient evidence to indicate intervention is likely to deliver meaningful benefits or outcomes
- It must be demonstrably safe and avoids the risk of harm
- Intervention should be cost-effective.

These are reflected in the value for money assessment of the NDIS (Supports for Participant) Rules.

However, there are complications that have made this difficult for decision makers to implement.

There is an ongoing conflict between what is described as best practice in historical versions of guidelines and other research and what government is willing to fund. In particular, previous research and guidelines for autistic children has suggested particular intensities of therapy and levels of Applied Behaviour Analysis (ABA)-based therapies are best practice for some children (or similar models). This evidence has been used successfully at AAT to overturn decisions by the NDIA that had been based on the contemporary best practice guidelines.

There is also the question of whether the intervention is demonstrably safe to the child and avoids the risk of harm. This is a particular question for ABA-based therapies and interventions and whether they are fully consistent with the social model of disability underpinning the NDIS, and respect for the rights of people with disability and children more broadly. We heard from autistic people and families about their experiences and perspectives of ABA-based therapies.

> *"There is increasing evidence clinical settings and "evidence-based practices" such as therapies that use applied behavioural analysis and ABA-like methods and theories (especially for autistic children) are causing long-term harm for short-term "normality". The focus of many of these practices is not support, it is to make a child look like other children, evidence is showing this causes long-term harm including lifelong PTSD." – Participant* [871]

> *"Supports should NOT be behavioural - disability advocates have repeatedly told us those supports are abusive and lead to trauma." – Carer* [872]

There is also the question of whether the intervention is cost-effective. Therapies or interventions based on ABA-based therapies are typically expensive to fund. This creates a challenge not just on whether evidence of a benefit exists, but whether there is also evidence of the cost-effectiveness of a particular service model. Particularly where an alternate model exists that is also evidence based and at substantially lower cost. This challenge has yet to be resolved by government in legislation or policy or through the AAT.

Resolving this tension requires government to be clear on what it is willing to fund as reasonable and necessary supports for children. Simply updating the best practice guidelines will not be enough to clarify the issue of reasonable and necessary supports. Government needs to go further to clarify what it is and is not willing to fund as best practice for children. This must be a priority matter for the new NDIS Evidence Committee to urgently address (see Action 23.2 and Chapter 6).

5.2.5.   Supporting families to demand best practice supports

Government has a responsibility to ensure families firstly understand what the concept of best practice is and why it will produce the best outcomes for their child. Best practice supports then need to be available to purchase.

To date, the NDIS has not been able to effectively inform, provide advice or support families to understand what best practice is or its potential benefits. There have been limited efforts to tackle this challenge, complicated by the limited understanding of best practice by NDIA frontline staff and in other service systems.

Families are often deeply sceptical about the concept and term best practice. From the time of a child's diagnosis, medical professionals have reinforced the importance of their expertise and advice. It is only after this that early childhood professionals have an opportunity to explain what best practice is and the importance of family-centred practice and supports in a natural setting.

This is often perceived as shifting work onto the family that would otherwise be done by a qualified therapist. It is therefore unsurprising that many families will prefer a therapy-focused approach.

"...my initial understanding should be my son and the therapist, but eventually I realised that when the key worker finished explaining to me that it should be a family-centred one and that's why I started empowering myself with how to help my son and not just relying on therapies." – Anonymous [873]

Consultations with families identified a very clear gap in understanding and awareness of best practice. Some families had never heard of key terms such as family centred practice or key workers. Some families were sceptical of best practice, likening it to a marketing term rather than a way to genuinely understand differences in service offerings. Other families were concerned that best practice involved services that were not neurodiversity affirming.

"It's also based on where you live. I live rural and its definitely not implemented where we are. Therapists spend one hour with the child, they weren't interacting with us. We are the caregivers we want to learn the tips and tricks. There's no additional supports or training for the parents to best support the child." – Carer [874]

"I feel like it's mentioned a fair bit these days but it's not really implemented. I have a 5 year old and a 3 year old, chucking all this therapy on one kid. Saying you need all this therapy is not really family-centred when it's like when can we actually spend time together? I think [how] it's actually able to [be] implemented needs a bit of work." – Carer [875]

Through the 10 years of the NDIS, families have shown a strong preference for maximising the number of therapy hours their child receives. We have heard that families will avoid any support that is perceived as reducing the therapy budget which is intended for their child.[876] This includes covering costs such as provider travel to deliver supports in a natural setting, or the administrative or non-face-to-face costs of delivering coordinated or more family-centred supports. It is completely understandable that families are currently making this choice. If some therapy for their child is beneficial it can be rational to believe that more therapy is better, particularly if the expertise of medical professionals has been constantly and consistently reinforced.

"There are some allied health professionals who seem to suggest a large amount of therapy which families report is doing not much more than stressing them out. It may be in some cases that the amount of recommended therapy is beneficial to the business model of the service provider rather than the family." – Down Syndrome Australia [877]

"There is a strong need to address the misconceptions held by some families that children with disabilities always need and have better outcomes when they're engaged with clinical services. However, on the flip side, if children need clinical services, they should be able to access them." – Victorian Council of Social Services [878]

"Therapy hourly rates are very high and generous, so they should include report writing and admin time, so they should not be allowed to charge extra non face to face time for this." – Carer [879]

"Both organisations charge double the amount the individual private therapists charge because the large organisations direct the therapists to charge routinely for "prep and follow up time" Plus the 1hr appoint Plus travel time... How could the pricing structure be redesigned to reward outcomes rather than the volume of transactions?- fee schedule should define that for every 30mins face to face appointment, the therapist can charge a MAXIMUM of 10mins non-face to face time. The length of non-face to face/prep and follow up time should NOT be left to the therapists discretion. I have been overcharged many times." – Carer [880]

This creates a vicious cycle where therapy delivered in clinical settings is valued highly and the work being done at home by the family to support the child is undervalued. It also means that families are not being supported to work therapeutic activities into their daily routines and creating opportunities for children to develop and practice their skills in the environments in which they will use them. The clinical approach can also inadvertently undermine a family's perception of themselves as experts in their own life and the life of their child and in control of outcomes.

Having help to identify opportunities for this within family routines or in natural settings, rather than having to carve out time to take the child to a therapist appointment away from the school or home, is a key element of best practice.

"Good support is when the therapist takes time to know our son in his daily environment, hence going to daycare. He is not excluded by having to leave to go to the doctor, but instead supported by being seen where he thrives. His educators also learn from the therapist what can be done to help and what is detrimental, and some of those strategies are actually helping other kids too." – Carer [881]

The limited availability of allied health professionals has also meant that even if families want to take a different approach, they can struggle to access support. Families have to take what is available and have little choice.

"Waitlists are beyond a joke, with most now being 12-18 months long before you are even able to get an initial intake appointment. We drive 50 minutes to my [child's] appointments 3 times a fortnight because I was lucky enough to secure a spot for [them]." – Carer [882]

5.2.6. Providers should be required to supply best practice supports

Efforts to increase the information, advice and support to families on what best practice is and its potential benefits can only go so far. Families cannot be expected to be experts in best practice and decipher whether a provider is delivering quality support based on best practice principles.

Government has a responsibility to ensure that best practice supports are what is available to purchase.

> *"Don't expect families to suddenly understand best practice. Make sure that is what providers are offering." – Child and Family Disability Alliance* [883]

Regulation of early childhood support providers

The NDIS Quality and Safeguarding Commission currently has an Early Childhood Support module, which is closely modelled on best practice principles.[884] However, only registered providers are required to meet this module and registration rates of early childhood providers is very low.

As at 30 June 2023, 95 per cent of families of children aged 0 to 6 either self or plan managed a portion of their budget.[885] This means they have the flexibility to use non-registered providers. With this level of demand from self-managing families there is little incentive for providers to register.

There has been an assumption that competition in the NDIS market would drive quality between providers. However, this requires that families are able to both easily identify differences in quality between providers and switch to an alternate provider. This has not been the reality. As described above, it is not reasonable to assume families are experts in service models and the highly constrained therapy market has meant that families are often having to take what is available rather than having a choice of different providers.

Enablers of best practice service delivery

Availability of a qualified and experienced workforce is critical to best practice supports. This includes allied health professionals, developmental educators, and early childhood educators.

The early childhood workforce has been impacted by broader capacity constraints in the allied health sector. This creates a strong incentive for service models that can maximise the number of clients within a day. From this perspective, it is far more efficient for a professional to deliver supports within a clinical model than to travel to deliver supports in natural settings. Whether travel time is paid for is irrelevant where children and families are on a waiting list and unable to get time with a professional.

The combination of providers being able to maximise revenues using a clinical model, families seeking to maximise therapy hours and workforce shortages is driving growth in the clinical therapy model. This is despite the best practice guidelines focusing on family-centred and inclusive approaches.

We have also heard Aboriginal and Torres Strait Islander participants including children in rural and remote settings are being particularly impacted by a shortage of qualified and culturally competent health professionals and service models.[886] General workforce shortages means it is inevitably harder to find staff outside of metropolitan areas and who are able to deliver culturally competent supports. This further entrenches inequity and inhibits progress towards Closing the Gap.

> **Case Study 12: Kimberley Aboriginal Medical Service[887]**
>
> The Kimberly Aboriginal Medical Service delivery of Remote Early Childhood Supports shows what is possible with an investment in an alternative approach when faced with workforce challenges.
>
> This model has been designed with community and for community and supports children and families in a culturally appropriate way. Family support workers act as cultural liaison for allied health professionals who visit the region up to five times per term.
>
> This model is covered in more detail in Chapter 1.

NDIS workforce shortages have been exacerbated by workforce challenges in the early childhood education sector.[888] This means the NDIS is competing for degree qualified early childhood educators in a constrained market. We also heard of structural disincentives to employing early childhood educators. In New South Wales, the Educational Services (Teachers) Award does not recognise this work for accreditation purposes.[889] This is despite the fact that early childhood educators are well equipped to understand the learning and developmental needs of children.[890] This means that providers are also competing for allied health professionals in an already tight labour market.

The lack of investment in allied health assistants has meant that the opportunity to increase allied health service capacity and availability has not been realised. Allied health assistants can help to improve equity of access to allied health services, including by operating under a hub-and-spoke model where an allied health professional isn't able to be regularly physically present in some locations. This allows face-to-face services to be delivered by an allied health assistant when the person would have otherwise likely gone without.

In addition to workforce supply issues, we heard there is a lack of structured pre and in-service training and professional development led by government for evidence based early childhood practice.[891] In 2017, the Joint Standing Committee on the NDIS noted that Early Childhood Intervention Australia was developing modules to help providers understand best practice but 'this does not address the absence of a consolidated, comprehensive hub of information from the NDIA about available practices and their substantiated benefit to certain cohorts'.[892]

Challenges in delivering transdisciplinary support

Difficulties in funding and delivering transdisciplinary approaches are not new. Providers reported similar difficulties delivering transdisciplinary practice pre-NDIS under the Helping Children with Autism and Better Start funding guidelines.[893]

Best practice involves a transdisciplinary team working together with support primarily being delivered in natural settings (see box 33 below for an introduction to different ways professionals can work with a child and family and each other). This usually involves incurring costs for non-face-to-face time, coordination and provider travel, with team members meeting regularly to discuss the progress of the child and how it can be optimised.

There is a reluctance from families to use NDIS funding in this way. We consistently heard families do not like to use funding on non-face-to-face services and provider travel. While non-face-to-face services are claimable under the price guide, there are no requirements and limited incentives for families to use funding for support in natural settings, appoint a key worker or promote collaboration of the team around the child.[894]

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Box 33: Approaches to teamwork | multidisciplinary, interdisciplinary and transdisciplinary[895]

There are a range of approaches to teamwork. It is often difficult for families to understand the differences in approaches when the definitions can be ambiguous and terminology is used interchangeably.

Each approach incrementally increases the level of collaboration and coordination between different professionals and centers the role of the family. Each also incrementally increases in benefits for the child and family, as well as difficulty for professionals to successfully implement.

Multidisciplinary refers to multiple disciplines of professionals working with a child. The emphasis is having multiple specialties and expertise available. However, the professionals work within their own discipline and have some limited coordination between each other.

Interdisciplinary refers to multiple disciplines of professionals working with a child and having formal channels for communication between each other. The emphasis is having a formal structure to encourage coordination. However, the professionals remain responsible for their respective disciplines and coordination is mostly limited to the formal channels.

Transdisciplinary refers to multiple disciplines of professionals working together with a child and family as a collaborative team. Removing the focus on individual roles or disciplines for professionals is a feature of the approach. This emphasises working across disciplinary boundaries.

A key worker (lead practitioner) plays a primary role in coordinating the intervention and delivering most (if not all) of the intervention. The effectiveness of the key worker is linked to the ability and willingness of the other professionals to release their disciplinary boundaries and work through the key worker. To be effective there must be sufficient time and resources to ensure a coordinated approach, including regular check-ins and team meetings of the transdisciplinary team and/or key worker with the family and child.

</div>

The NDIS has led to a significant fragmentation of the therapy market. A proliferation of sole traders and small to medium enterprises has emerged in response to the current pricing and commercial arrangements. An unregistered provider with very low overheads can be highly viable under the current price caps for therapy.

This fragmentation of providers makes it more challenging to coordinate across services and create a team around the child. Having multiple providers delivering supports for a child makes it far more difficult to organically achieve a transdisciplinary approach. None of the providers are necessarily being asked or paid to coordinate with the other providers. This means the workload falls to the family to organise and coordinate providers. Few families receive assistance from a Support Coordinator to meet this additional workload.

Disjointed service delivery increases the likelihood that providers are working inconsistently or duplicating effort.

> *"...many families are accessing multiple different providers/therapists and getting piecemeal intervention which goes against best practice guidelines." – Non-government organisation* [896]

5.2.7. A best practice approach to supporting children and families must be embedded in the NDIS

We are proposing a package of reforms to ensure best practice supports are delivered for children and families. Given there have been a number of reasons why best practice intervention has not become the norm in the NDIS, we need a suite of reforms to ensure significant change. There is no one magic solution.

The future approach should be consistently focused on the family and ensure they have the information, advice and support to make informed decisions. Families should have dedicated support from a Lead Practitioner to help coordinate supports in a best practice way and prevent this workload continuing to fall onto already stretched families. This is in addition to the general support also available to all people with disability and their families from a Navigator.

The future approach should also have much stronger requirements for providers to deliver supports in a best practice way. Providers will be required to meet the new regulatory framework (see Action 17.1). This means that all providers delivering early intervention supports for children will need to be registered. There will need to be support for providers to deliver on the best practice approach, including support for workforce development and other market incentives (such as changes to the pricing and commercial arrangements).

Underpinning this approach is the immediate need to advance the update of the guidance for best practice in early childhood intervention (existing action 2.4 of the Early Childhood Targeted Action Plan in the ADS) and clarify what are reasonable and necessary supports for children.[897] These steps should be the highest priorities for government.

Requiring best practice supports will result in better outcomes for children and families. There are four main areas of change proposed:

Figure 58: Four main areas of change for best practice supports

Supporting families to demand best practice supports	**1) Greater information on best practice**	• Requires significantly more information and guidance for families. • Information should clearly explain what best practice is and what to look for in choosing a provider.
	2) Dedicated advice and support from a Lead Practitioner	• Requires a Lead Practitioner to support all children and families. • Lead Practitioners would be the agent of the child and family. • They would help ensure that a best-practice approach is used across all early intervention supports for the child and family.
Requiring providers to supply best practice supports	**3) Regulation of early childhood support providers**	• Requires all providers delivering early intervention supports to be registered. • The existing Early Childhood Supports Module should be updated and strengthened.
	4) Enablers of best practice service delivery	• Requires support for providers to deliver a best practice approach. • Would include support for workforce attraction and development. • It should also ensure providers can viably deliver a best practice service model.

Overview of the future approach

The first step in embedding a best practice approach is to reach agreement about evidence based intervention and what constitutes best practice. While the overall direction is clear, the additional details which will become available from action 2.4 of the Targeted Action Plan in the ADS should be an urgent priority for government.

DSS must urgently progress the existing review of the guidance for best practice in early childhood intervention and provide an updated framework that can be applied consistently across Australia to support young children with disability or developmental concerns and their families.[898] This should also include an expansion of the best practice principles and guidelines to become a contemporary practice framework with associated tools, examples and resources.[899] Importantly, the work to complete action 2.4 of the Targeted Action Plan should add-to, but not delay, the proposed reforms.

Government must also clarify what it is and isn't willing to fund as best practice for children in the NDIS. This should be codified in the NDIS Rules to give guidance to decision makers on how to determine what reasonable and necessary best practice supports are for children. This must address the question of when (if ever) the NDIS should fund more intensive and expensive service models, where a more cost-effective alternate service model exists that is aligned with best practice. This must resolve the uncertainty in how value for money is currently assessed within the *NDIS (Supports for Participants) Rules 2016* (see Section 2.2.1) and what can be considered a comparable support for the purpose of making a value for money assessment.

These actions will need to be supported by information and guidance about best practice that is widely available for families and providers (see below for more detail). The revised guidance should also be embedded into the work of mainstream services and the Navigators, Lead Practitioners and NDIA Needs Assessors.

Supporting families to demand best practice supports

In the future, there needs to be significantly more support for families. This needs to be a combination of information so they are able to be better informed, understand their child's needs, feel empowered and ensure they are not overloaded. This should be underpinned by dedicated support from a Lead Practitioner (the term the Review uses for a key worker).

Greater information on best practice

More information, support and guidance needs to be provided to families about best practice and the early childhood approach. Communication is key to ensuring families can understand the benefits of family centred practice. Information and resources should be developed and continuously updated to ensure families have access to information that is easy to read, simple, clear and timely.

Multiple organisations, including the NDIA, have developed resources and information, but there is no centralised repository. An immediate stocktake is required to collate what is already available and fit for purpose. This should identify gaps to be resolved.

At a minimum, there should be simple, easy to understand resources that give an overview of best practice generally and each of the eight principles of best practice (see Figure 56 above for the principles). It should include information on general child development and how families can practically support their children's development through everyday routines. These should include real life examples from other families who have gone before and can share their experiences. Resources should be made available in multiple mediums, in diverse languages and be designed with the communities they are intended for. Further information about ensuring information resources are appropriately tailored for diverse audiences is provided in Section 5.3.

Figure 59: Current and future state for Lead Practitioner role

Current State: Fragmented and Individual Supports
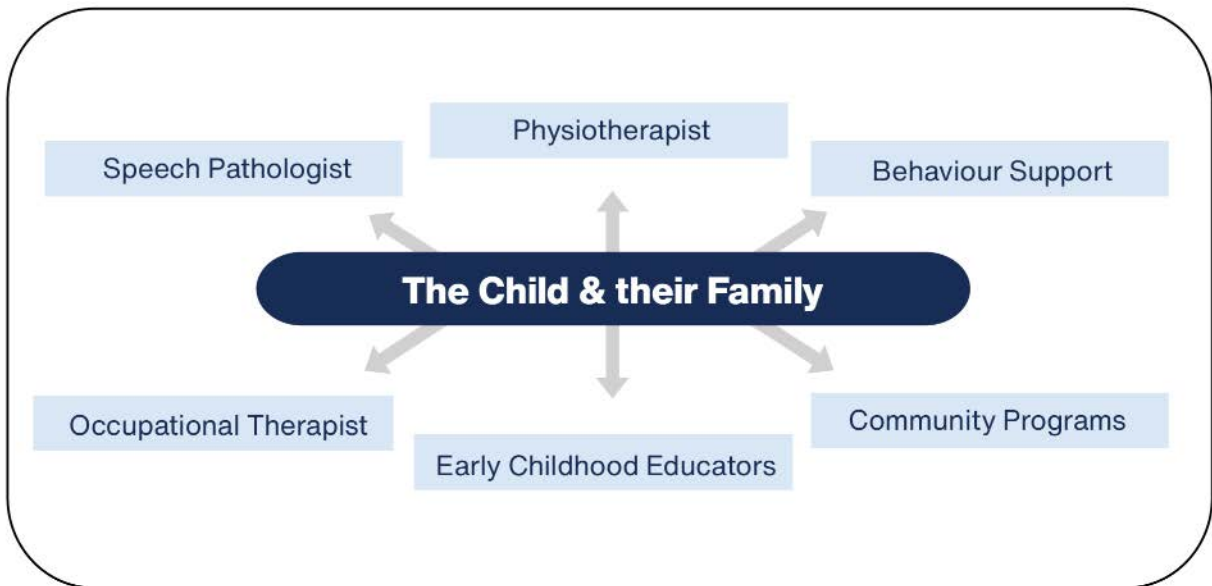
Future State: Dedicated Lead Practitioners coordinating supports
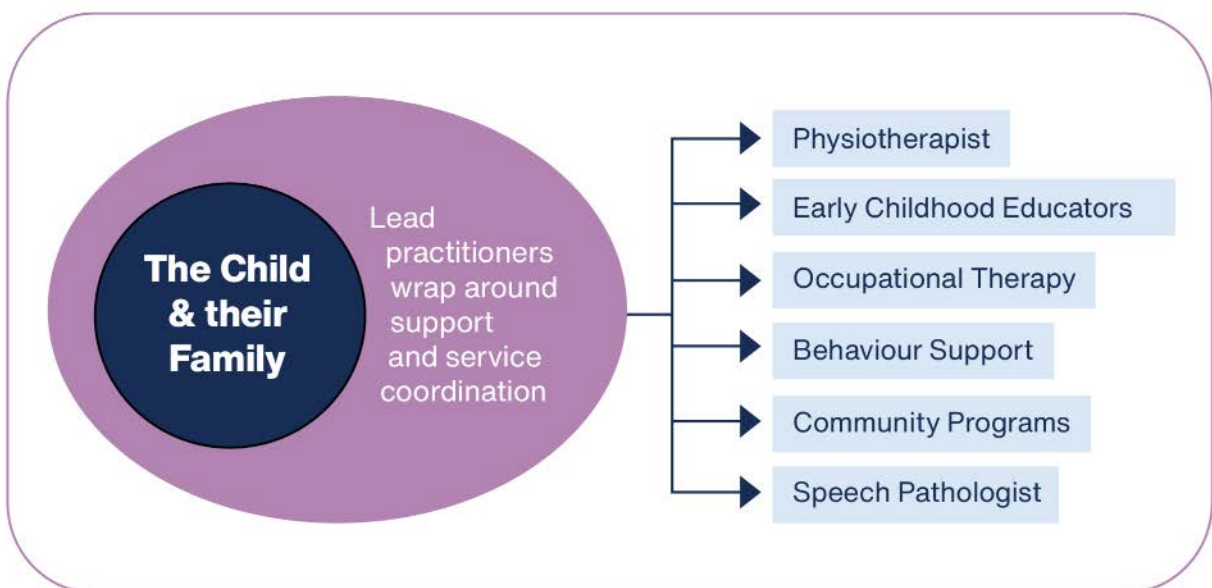
The NDIA website is not currently child or family friendly. This should be refreshed to be more user-centric in line with the Australian Government Digital Service Standard. There should be a dedicated part of the NDIA website aimed at families that houses the centralised information. This requires user testing to ensure it is fit for purpose. Government needs to learn from the poor implementation of the Disability Gateway. Simply creating a website with information is not enough. It must be tailored to how people can and want to engage with it.

It should also include family friendly resources to help understand the NDIS early childhood approach, including the role of the Navigator and Lead Practitioner and what provider registration means. A refreshed approach to the website should also provide a valuable resource for Navigators and Lead Practitioners and make their roles more efficient and effective (including providing consistent advice and referrals to foundational supports).

<u>Dedicated advice and support from a Lead Practitioner</u>

We are proposing that all children who are NDIS participants and their families receive support from a Lead Practitioner. The Lead Practitioner will act as a key worker to help families find best practice supports that will best support their child and/or children. Lead Practitioners will take a holistic approach to understand the strengths and circumstances of individual families and ensure that support is appropriately tailored. This should include additional time and tailored assistance to support single parent families, families from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander families, parents with disabilities and families with multiple children with disability. The key functions of the Lead Practitioner are illustrated in Figure 60 below.

The Lead Practitioner should be required to have expertise in child development to be able to support families in an evidence informed, principles based way. They should be a qualified allied health practitioner, developmental educator or early childhood educator who is trained in an approach based on best practice principles. They should be a registered provider and meet specific service delivery requirements in order to be approved to provide the support. There will be dedicated funding to cover the cost of the Lead Practitioner activities.

Families should be able to choose from more than one organisation and provide preferences for a particular Lead Practitioner or a particular discipline that reflects the needs of their child.

Box 34: Overview of how the Lead Practitioner model will work

Families should have dedicated support from a Lead Practitioner who should be an agent of the child and family. Ideally a sustained and trusting relationship will be built over time. The Lead Practitioner will play a coordination role in bringing together the team around the child and linking the child and family with local services and the community. They will help to ensure a best-practice and transdisciplinary approach is used across all early intervention supports for the child and family. They will help ensure that supports are primarily being delivered in the home or community, ensuring skills can be taught, learnt and reinforced in natural settings.

Families will be able to choose a Lead Practitioner where they know of an approved Lead Practitioner who is available. Where they don't know a Lead Practitioner, they can express a preference for a preferred discipline and expertise of Lead Practitioner and the Navigator can provide different options of suitable Lead Practitioners. The needs assessment will help to provide guidance on what supports are required and therefore which discipline or expertise is more relevant. The Navigator will also assist where a family has an existing Lead

Practitioner and would like to switch to another or would like the Lead Practitioner to support a second child who is also a participant.

The approach to funding the Lead Practitioner is provided in the budget setting section below (see Section 5.4.3). A Lead Practitioner should ideally have a level of funding to cover the coordination and administrative costs of supporting the family, as a well as for providing supports from within their scope of practice. They should also be able to directly provide services from outside their discipline with supervision and support from other relevant professionals chosen by the family. This would require the family choosing to use some of the flexible budget to receive more support that is delivered by the Lead Practitioner. This would be consistent with a transdisciplinary approach and could provide greater coordination and service integration benefits. However, this must be monitored closely by the Navigator to provide independent oversight of how the flexible budget is used to ensure the benefits of integrated supports outweigh the risk of a potential conflict of interest.

The Lead Practitioner will provide support across the five key areas in Figure 60.

Figure 60: Overview of the key functions of the Lead Practitioner [900]

	What the Lead Practitioner will do	**Why this is important**
Identifying and addressing needs	• Work with families to identify and respond to needs of the child and family, including connecting to supports or building networks (such as counselling and sibling support). • Use a 'routines based' approach to embed learning opportunities in activities that happen regularly. This should build on the strengths and interests of the family.	• Interventions grounded in everyday activities (such as meal and bath times) recognise the time and learning opportunities in daily activities, make therapy more achievable and less like homework or an extra task. • Identify and respond to key challenges such toileting, feeding.
Service coordination	• Play a key contact role with the family and help the family coordinate the team of services and professionals around the child (other providers chosen by the family). • Bring together an integrated and holistic approach to supporting the child and family.	• Move from single disciplines working in isolation and towards a more coordinated approach around the child and family. • Reduce stress and intrusion in family life and mitigate risk of therapy burn out. • Align with and support whole family needs.
Information and advice	• Have particular expertise in child development and be a trusted source of information and advice to the family. • Have strong local connections and experience in the community. This should be used to support children and families to access inclusive local activities and settings.	• Supports the family to be informed decision makers and builds their skills and confidence to respond to their child's needs. • Accessible and inclusive mainstream, community or foundational supports can be highly beneficial for the child and/or family.
Emotional support	• Provide emotional support to the family. This should be a combination of direct support and assisting families to build connections to strengthen their informal support networks.	• Families experience additional stressors and can be socially isolated. • Well supported families are better able to respond to and support their child's needs.
Develop self-advocacy skills	• Support families to develop skills, knowledge and connections for self-advocacy. • Guide the family on strategies to build the independence and decision making capacity of the child as they grow older.	• Children and families experience exclusion, discrimination and ableism. • Children and families need to be supported with practical skills, strategies and confidence to self-advocate when they experience this.

5.2.8. Requiring providers to supply best practice supports

In the future, there should be stronger requirements and incentives for providers to deliver supports in a best practice way. Providers should be required to meet the new regulatory framework and adopt best practice in delivering supports. They should also be supported and incentivised to deliver supports that are consistent with the best practice principles.

This is needed to ensure supports are safe, consistent with evidence and best practice and produce good outcomes for children and families.

<u>Regulation of early childhood support providers</u>

We are proposing the introduction of a new risk-proportionate model for regulation of providers and workers. This involves mandatory registration or enrolment of all NDIS providers. The specific requirements for providers will be proportionate to the risks of providers' activities and operations. Further detail on the proposed regulatory model can be found in Recommendation 17 and Chapter 5.

Children are in a critical development period during the early years with experiences in early childhood potentially impacting outcomes across their life. Early intervention can address issues early and support children to realise their potential.[901] This means that there is a high inherent risk in the delivery of early childhood supports. The consequence of supports being delivered improperly, causing harm or to a low level of quality is significant. This means that providers delivering early intervention supports should be registered in recognition of the significant level of risk and impact of harmful, unsafe or poor quality supports being delivered to children.

> *"...only NDIS providers that are registered to provide early childhood services to children under 7 years old are required to undergo specific training on working with children. This module covers the rights of child participants, practices and procedures to manage risk and create a safe environment for children, and compliance with relevant state and territory legislation relating to the reporting of risk of harm to children." – Commission for Children and Young People (Victoria)[902]*

> *"Registration is not costly. A focus on quality is. Why would you not be insisting that providers maintain a focus on quality? If you want best practice, if you want evidence based interventions, if you want inclusion then you must insist on it. You need to lay down the rules that say this is what quality looks like and we will only pay for that." – Provider[903]*

> *"We have grave concerns that there is no child safety lens at all when it comes to quality and safeguards around the NDIS and working with children specifically. A working with children check is not enough. Working with children checks last for five years. People don't check their currency in the State of Victoria anyway on the Justice website, even though they know they can. We feel as though any person who is being*

funded by the NDIS to work with a child has to do an additional training which pertains to child safety and the national child safety principles." – Advocate[904]

Those delivering early intervention supports would also need to meet an updated Early Childhood Supports Module which is aligned with best practice. The existing Practice Standard should be strengthened to effectively capture the roles and expectations of Lead Practitioners and other early childhood providers, including the focus on more evidence-based interventions. In updating the Practice Standard, consideration should be given to strengthening the module once the work to be undertaken by DSS to update the guidance for best practice in early childhood intervention (existing action 2.4 of the Early Childhood Targeted Action Plan in the ADS) is completed. As well as including more detailed evidence-informed quality indicators.

"...the existing set of Best Practice Principles need to be expanded to become a fully-fledged practice framework with tools, examples and resources" – Professionals and Researchers in Early Childhood Intervention[905]

This will bring all providers working with younger children into alignment under the Early Childhood Supports Module. It is consistent with one of the mechanisms considered by the ECEI Reset Project to enhance compliance with Practice Standards.[906]

The review and update of the Early Childhood Supports Module should be undertaken in conjunction with an early focus by the new Deputy Commissioner for Quality at the National Disability Supports Quality and Safeguards Commission on driving quality in the delivery of these supports (see Action 12.1). The Deputy Commissioner for Quality would promote best practice by building and disseminating the evidence base and guidance on good practice for all early intervention supports. This includes a particular focus on ways to drive quality in the delivery of these supports and improve outcomes for children, as well as collating and disseminating research to support families, Navigators, Lead Practitioners and NDIA staff with advice on effective early intervention strategies.

Enablers of best practice service delivery

There must be support for providers to deliver on the best practice approach, including support for workforce development and other market incentives (such as changes to the pricing and commercial arrangements). Given the long lead times for workforce development, efforts to increase support for training, coaching and supervision should be prioritised by government.

The future early childhood workforce should be a priority for government, including through its considerations of broader findings and recommendations that may impact the workforce (such as the Early Years Strategy, National Autism Strategy, and Productivity Commission inquiry into the early childhood education and care sector).

This will require a targeted and strategic approach to ensure there is an adequate supply of professionals trained and skilled in delivering best practice supports for children with developmental delay or disability. DSS should lead this approach as part of their role leading the update of the guidelines for best practice early intervention, the Early Years Strategy, National

Autism Strategy and responsibility for workforce policy in the NDIS. The approach will need to consider ways to retain and upskill the existing skilled workforce and how to support them to transition to new ways of working, as well as attracting new professionals to work in the early childhood intervention sector.

This needs to be underpinned by further enabling changes to allow providers to be able to viably deliver best practice supports. This should include consideration of the pricing arrangements for early childhood supports to enable providers to appropriately train and upskill their staff. It should ensure that funding can be redirected by families towards aspects of service that are consistent with best practice. There is a critical need to ensure the cost of travel to the home or other natural settings and the cost of transdisciplinary consultations and coordination, coaching and supervision are all adequately resourced.

> *"Incentivise providers to deliver and families to request services in natural settings i.e. home, community, early childhood education settings and school so that families are happy to pay for travel: The cost of travel is seen as 'reducing' their 'therapy budget' and therefore, families opt for clinic-based models. Help families to understand routine-based support in natural setting is an evidenced-based practice as it improves their child's service outcomes and supports inclusion." – Early Childhood Intervention Best Practice Network[907]*

> *"If we do it at home then everyone can see it. I would prefer at home, but as people have mentioned, the costs and travel." – Carer[908]*

> *"Multiple children, you can't be carting them from clinic to clinic, appointment to appointment. We live rurally, so we can't have them travel to us – would use up all our budget." – Carer[909]*

> *"Given the importance of families and caregivers within their child's journey and benefits of providing therapy within the child's natural environment, budgets allocated specifically for travel must be introduced. Incorporating additional travel funding within plans allows the sector to provide these services wherever the child is without affecting their therapy allocation and lessens the impact on the family of having to undertake the travel burden to receive services." – Speech Pathology Australia[910]*

> *"Adopt a multidisciplinary, coordinated, and goal focussed approach that includes the children (appropriate to age), allied health professionals, their families and support networks. Where relevant include educators, teachers, sport coaches, etc. Focus on involving children and their families in the therapy process." – Australian Physiotherapy Association[911]*

5.2.9. Action & Implementation Details

📑 Action 6.5: The National Disability Insurance Agency, in partnership with the Department of Social Services and the National Disability Supports Quality and Safeguards Commission, should require early intervention capacity building supports for children be based on best practice principles and evidence.

This would involve the introduction of a dedicated Lead Practitioner role and a revised regulatory model for providers delivering support to children under the age of 9.

Lead Practitioners and all other providers delivering supports to children should be registered, consistent with the graduated risk-proportionate regulatory model (see Action 17.1) and supported by strengthened Early Childhood Practice Standards. The Lead Practitioner should be an agent of the family and work with families in the best interests of the child to identify and address needs, connect them to foundational and mainstream supports, and provide information, advice and coaching to support their child's development.

The Lead Practitioner should be funded from participant budgets, including for the delivery of NDIS supports within their scope of practice. The amount of support available to the child from the Lead Practitioner should be determined through the needs assessment (see Action 6.4). Specific service delivery requirements for the Lead Practitioner will be set by the NDIA through contractual arrangements. There should be sufficient market depth to allow families to have a choice of Lead Practitioner and contestability to incentivise higher performance by Lead Practitioners, including allowing new entrants to enter the market.

These changes should be supported by far greater consumer education and information, support for provider workforce development and other market incentives (such as changes to the pricing and commercial arrangements) to support the increased adoption of capacity building supports based on best practice principles and evidence.

Implementation detail:

- The Australian Government, through the National Disability Supports Quality and Safeguards Commission should require that all providers delivering supports to children meet the new regulatory framework, including mandatory registration for providers delivering capacity building supports to children under the age of 9 (see Action on 17.1).
- The NDIS Experience Design Office should design and test a Lead Practitioner role to support children under the age of 9 and their families. This role should include the following:
  - Information and advice:
    - o Sharing information and materials with families.
    - o Providing deep professional and community expertise.

- Identifying and addressing needs:

  o Working alongside families to identify and respond to the needs of the child and family within their area of expertise, including providing practical strategies and support for child development.

  o Identifying opportunities to connect to mainstream and foundational supports and build informal networks.

  o Using a routines-based approach to identify and embed strengths-based learning opportunities in activities that happen regularly.

- Service coordination:

  o Taking on the role as key point of contact role with the family and help the family coordinate the team of services and professionals around the child and bring together a unified approach.

  o Supporting a shift from single disciplines working in isolation to a transdisciplinary approach and having a coordinated team around the child and family.

- Emotional support:

  o Providing emotional support to the family, either directly or by assisting families to build connections to strengthen their informal support networks.

- Self-advocacy:

  o Helping families to develop skills, knowledge and connections for self-advocacy. Empowering children and families with practical skills and expertise will ensure they are well equipped to navigate future challenges.

- The NDIS Experience Design Office (see Action 24.3) should design the Lead Practitioner role with the following considerations:

  - The specific service model(s) and service requirements of the Lead Practitioner role should be established in a contractual agreement between the NDIA and Lead Practitioners.

  - The Navigator plays an important role in monitoring any conflicts of interest in regards to the use of the flexible budget to purchase additional supports from a Lead Practitioner.

  - Lead Practitioners should have clearly defined and transparent caseloads.

  - Lead Practitioners must be registered with the new National Disability Supports Quality and Safeguards Commission to ensure appropriate safeguarding (See Action 17.1).

  - Design must involve people with disability who have complex needs including, people with an intellectual disability, people from First Nations communities, people from

culturally and linguistically diverse backgrounds and the sector and technical experts to ensure it captures the complex and intersecting needs of people with disability.

- Lead Practitioner services must be delivered in a culturally safe and appropriate way by appropriately trained staff.

- Staff delivering Lead Practitioner functions must have strong local knowledge, and the ability to deliver services in a trauma-informed way.

- People with disability expertise and lived experience of disability should be supported into Lead Practitioner roles wherever appropriate.

5.3. Access to the NDIS for children is inconsistent, inequitable and not based on need

Having an effective access pathway is an essential component of a needs-based scheme. Being effective means that access is timely, easy to navigate and consistent - so children and families can get the right supports at the right time.

We have heard the current way to access the NDIS is difficult or challenging for the majority of families. Some children and families are having to compile significant evidence to support an access request, while others are enduring long waiting lists to access a specialist for a diagnosis. Multiple access pathways into the same early childhood approach is resulting in inconsistent and inequitable outcomes. Some children are not receiving the same access decision or same level of support as their peers with similar needs.

A much stronger link between access to the NDIS and need is necessary to ensure children with developmental concerns and disability are able to access the right supports at the right time. This should be achieved by introducing a dynamic and responsive Access Request Form to collect more consistent evidence to inform access decisions and a standardised approach to assessing whether an applicant meets eligibility requirements. This should be coupled with removal of automatic access under Access Lists. This would improve the consistency and transparency of the experience for all applicants to ensure the NDIS remains needs based and sustainable.

This should be supported by the proposed investments in foundational supports so children with developmental concerns, delay or disability who do not require an individualised budget are warmly referred to supports outside the NDIS that meet their needs.

These proposed reforms are closely linked to a revised access pathway for early intervention. The detail of those reforms is set out in Section 2.1.2. This section is focused on access for those who are younger than 9. The intent and principles of the new access pathway is consistent for applicants and participants under and over the age of 9.

5.3.1. The current pathway into the NDIS is not striking the right balance to ensure access to the NDIS is based on need

Some children can access the NDIS relatively easily and others face significant barriers due to complexity of the process, waitlists for specialists or not having Early Childhood Partners available in their area. This is inequitable.

Decisions about developmental delay remain subjective and inconsistent. The continued use of Access Lists have created a focus on particular diagnoses.

A more consistent approach to access is essential for ensuring children get the right supports at the right time and ensuring the sustainable operation of the NDIS.

5.3.2. There are different access pathways for children

There are three distinct pathways for children to access the NDIS set out in the *National Disability Insurance Scheme Act 2013* (NDIS Act); section 24 (disability requirements), section 25 (early intervention requirements) for those with permanent impairment, and section 25 (early intervention requirements) for those with developmental delay.

As described in the participant's section (see Section 2.1.2), the introduction of diagnostic lists (Access Lists) by the NDIA during the roll-out of the NDIS has created an additional pathway where some applicants experience very different evidence requirements to prove eligibility relative to those not covered by an Access List. Consistent with older applicants, the access process via a list is determined by the diagnosis of the applicant. See Figure 61 below for an overview of the different access pathways for children.

Figure 61: High-level overview of the different access pathways for children

Section 24 of the NDIS Act	**Section 25** of the NDIS Act		**Access Lists**
Disability requirements Access under section 24 for people with disability with permanent impairment, substantially reduced functional capacity and lifetime support needs	**Early intervention requirements - permanent impairment** Access under section 25 for people with disability with permanent impairment who are likely to benefit from early intervention supports and are best supported by the NDIS	**Early intervention requirements – developmental delay** Access under section 25 for children with developmental delay (defined under section 9) who are likely to benefit from early intervention supports and are best supported by the NDIS	**Automatic access:** **List A** Conditions likely to meet section 24 eligibility **List D** Conditions for those under 7 likely to meet section 25 eligibility **Streamlined access:** **List B** Conditions likely to meet permanent impairment criteria for section 24 or 25

Children primarily access the NDIS through early intervention criteria of the NDIS Act. The majority of these children enter under developmental delay or global developmental delay criteria (Figure 62). Just over half (51 per cent) of access decisions for the NDIS in 2022 were for children younger than 9. Of these:

- 84 per cent were for access under section 25 (early intervention requirements) of the NDIS Act
- 87 per cent of the children younger than 9 entering under section 25 (early intervention requirements), accessed with developmental delay or global developmental delay.

Figure 62: Overview of the access pathways used by children
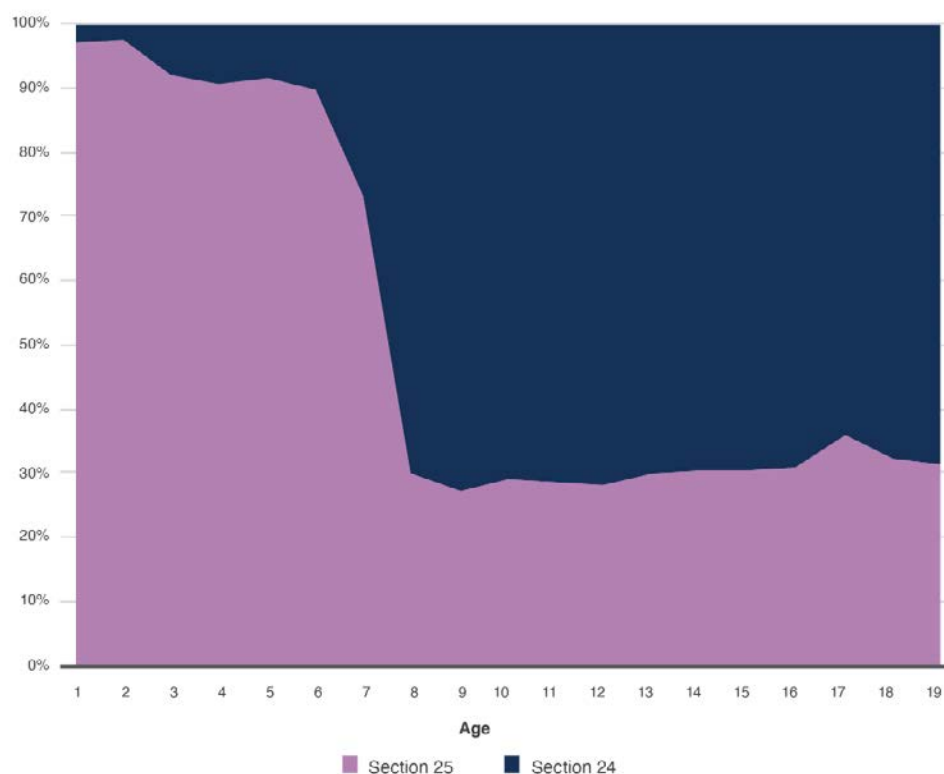
5.3.3.   Making an access request for the NDIS

Partners in the Community work with the NDIA to deliver the NDIS. Early Childhood Partners are the NDIA's Partners in the Community for children and their families younger than 9. They help deliver the early childhood approach in metropolitan, regional and rural areas of Australia. They work with families to provide them with information, connections and support based on their child's needs and circumstances. This can range from information on child development, connections to services or supports, direct service delivery through to assisting with applications and planning for the NDIS.

Early Childhood Partners play an important role in the access pathway for children. Families are encouraged to engage with their local Early Childhood Partner before making an access request. This is to give an opportunity to provide more pre-access support to children and families and ensure they are connected to the right type of supports.

Access with developmental delay

Early Childhood Partners play a significant role for children with developmental delay making an access request to the NDIS. Most families of children with developmental delay work with Early Childhood Partners to gather information about their child to understand whether they meet developmental delay criteria and collect evidence to support the access request. The process includes talking to families, reading reports, conducting observations and using assessment and screening tools to understand a child's development.

The exception is in remote and very remote locations where there are no Early Childhood Partners. Children and families in these areas need to make an access request directly to the NDIA who will then work with health professionals, education, other community members and families to gather the information to make an access request. Remote Community Connectors can also help with applying for the NDIS.

Access under the disability requirements or permanent impairment

Children accessing the NDIS through the disability requirements (section 24 of the NDIS Act) or permanent impairment (section 25 of the NDIS Act) can make access requests directly to the NDIA.

Consistent with older applicants, children and their families can directly apply by completing an Access Request Form or making a Verbal Access Request. Treating professionals provide written information to support access requests, such as reports, letters or assessments of evidence of disability, need for early intervention, and/or functional impairment. They may also complete the Supporting Evidence Form.

5.3.4. There are inconsistencies with how evidence is collected for children

We have heard about many challenges and barriers that applicants of all ages and their families currently encounter making an access request to the NDIS (see Section 2.1.1).

Support from Early Childhood Partners through the access pathway does make the process easier for many children and families. It is however not a consistently straightforward or well understood pathway. In their submission, the Child + Family Disability Alliance indicated that based on consultations with 237 families, 'more than 57 per cent said applying for the NDIS was difficult or challenging in some way'.[912] Mainstream services appear to have little knowledge of the NDIS access pathway and are mostly unable to help.[913] This means those who need support the most are missing out.

> *"It is our observation that many children at greatest need of NDIS services, including those who are poor or live in remote locations, have trouble accessing the NDIS in comparison to children of affluent and empowered parents." – Neurodevelopmental and Behavioural Paediatric Society of Australasia [914]*

> *"The pathway options that have been set up for the scheme are fragmented at best and designed to discourage people application at worst. The ECEI pathway has become a nightmare with ECEI providers claiming to be the only access point to NDIA. This is simply untrue. Families who share their confidences with a GP, family support service, child care provider should be encouraged to seek support with an application from anyone that they trust. I have been formally reprimanded many times for assisting families to complete an application because their attempts to contact the local ECEI have left them demoralised or ignored. Outsourcing to Partners LAC has been a complete fail. It has fractured the community infrastructure and connection that has cultivated in small communities over decades." – Anonymous [915]*

For children over the age of 6, we also heard that access decisions become heavily focused on diagnoses rather than impairment. This leads to families incurring significant costs obtaining a diagnosis and a delay in accessing supports while waiting for a specialist appointment.[916]

> *"I started, noticing delays and developmental issues with her when she was around 4. But she was my first child, so I just thought her behaviors were normal. I didn't know any different. So when she started prep that's when I was brought up to me by a teacher that we should probably investigate Adhd as her first diagnosis NDIS was never mentioned to me. It was actually through my own research on how I am able to pay for therapies or these assessments, because even just getting into the NDIS was really difficult for her not having diagnosis back. Then even Adhd, when she eventually got it, she fell between the bracket of 6 to 7 years, and we got denied access, even though she had all these reports with all her behavioral issues… It wasn't until that we forked out a lot of money for the autism assessment that she was granted access." – Parent[917]*

> *"The eligibility criteria currently in effect further compounds the issue and can result in children who have vision loss being refused access to the scheme. Sometimes exclusion based on eligibility criteria occurs because it is possible to detect vision loss very early, but the cause of that vision loss is more difficult to establish. In the absence of a diagnosis included on one of the scheme's access lists, children are only able to access the scheme if developmental delay can be demonstrated. It's ironic, given that the aim should be to prevent developmental delay rather than delay care until a diagnosis is reached or developmental delay is manifested." – Vision 2020 Australia[918]*

> *"It took 3 weeks to get in to the GP, 6 months for a paediatrician appointment to get a letter for NDIS, 4 or 5 months for the NDIS application process to happen, and then 6 months to get in to a speech therapist." – Carer[919]*

Analysis completed by the Review suggests participation in the NDIS is lower than expected for Aboriginal and Torres Strait Islander and culturally and linguistically diverse people (see Chapter 7). The costs of obtaining diagnoses can be prohibitive for these especially newly arrived residents. Aboriginal and Torres Strait Islander families also face barriers relating to intergenerational trauma, location, access to culturally appropriate and responsive services and cultural differences in seeking access or support.[920]

> *"CALD and newly arrived residents are vulnerable as they can find that obtaining evidence is costly, problematic and confusing." – National Ethnic Disability Alliance[921]*

> *"The use of medical model-based diagnostic testing as the basis to access the NDIS is an example of institutional discrimination as it actively excludes First Nations people from participating in the NDIS." – First Peoples Disability Network[922]*

While the Early Childhood Partners are expected to play a key role in assisting with access, we have heard about a number of issues, including a lack of consistency and time to perform their role effectively. There were doubts that developmental delay was being consistently assessed across organisations, and that the information gathering and assessment function was not appropriately reflected in Key Performance Indicators and contracts.

Multiple Early Childhood Partner organisations noted concerns about consistency of assessing developmental delay across different organisations. We heard that Early Childhood Partners are subject to competency checks for plan recommendations, but not access recommendations.[923] As of June 2023, 98 per cent of access applications for developmental delay were successfully accepted by the NDIA. This is significantly higher than the general access rate of 85 per cent across other primary disability groups.[924]

> *"…we are making this decision, whether they will get on. But, even just that consistency, "Do I interpret this child the same as what would you say they see, as what would a coordinator in another…" And, even when we're training and stuff, there's some resources, but there's not as though [sic] clear. What you interpret as a substantial impact in a domain versus someone else, that is still, again, a big call. I don't know." – Anonymous[925]*

The Early Childhood Partners also appear to have significant capacity constraints, due to the high volume of access and planning activities required and the limitations of their contracts. One Early Childhood Partner for example estimated that it took six hours to do the information gathering and assessment function well for developmental delay, but they believed less than five hours was allowed for in their contract. This raises concerns about whether the fidelity of the process can be assured when under strain.

> *"When we look at our current contract and the volume of work, four out of five children are coming through under developmental delay…there's a lot of work that happens before that's even considered in our KPIs or our contract." – Anonymous[926]*

The absence of Early Childhood Partners in remote and very remote areas means that children and families in these areas have less support to access the NDIS. This is evident in the lower access met rates for children younger than 9 in remote (93 per cent) and very remote (91 per cent) communities compared with metropolitan and regional communities (96 per cent).[927] This is despite processes within the NDIA to expedite the consideration of access requests from these areas.

> *"And if you've ever looked at the statistics of children who have developmental delay in Darwin, it is not consistent with the children who have developmental delay accessing NDIS in other parts of the territory. Which says more about their ability to access a person who can support them, than it does around children needing support." – Anonymous[928]*

Children with developmental delay in remote and very remote areas also face different evidence requirements to access the NDIS. This is because there are different forms that can be completed to provide evidence that a child meets the developmental delay criteria. Early Childhood Partners will complete the Evidence of Developmental Delay form with families. Where an Early Childhood Partner is not available, external health, allied health or early childhood educators will complete an Evidence of Developmental Delay for Children in Remote and Very Remote Areas form with families.

Despite both being used to inform a decision about meeting developmental delay criteria, these forms have different evidence requirements. In particular, the Evidence of Developmental Delay for Children in Remote and Very Remote Areas form includes prompts to provide evidence that is not included in the Evidence of Developmental Delay form. This means that children in remote and very remote areas arguably have to meet a higher evidence bar without the benefit of support from an Early Childhood Partner. The rationale for the different forms is unclear. The difference in access rates suggests there is inequity in how this is currently working. See Figure 63 below for a summary of similarities and differences in the evidence requirements of the forms.

> *"We want to make informed decisions. And I think if they were to review the plans, the EODD forms coming through, there are children meeting access that possibly shouldn't or would be better supported in early supports and there's definitely not national consistency in completing those forms." – Anonymous*[929]

Figure 63: Summary of similarities and differences between different evidence forms (each row represents an element of developmental delay criteria (section 9 of the NDIS Act))

	Evidence of Developmental Delay for Children in Remote and Very Remote Areas form	Evidence of Developmental Delay form
Substantial reduction in functional capacity and delay	Space to describe functional delay across four developmental areas.	Function is described across four developmental domains and space to compare to same aged children.
Service response from more than one professional working as a team to support the child	Space to describe: • Main developmental areas requiring support. • Allied health or specialised early childhood supports needed. • Settings supports are required in.	Pre-populated text indicates a team response is required. Option to insert qualifications of professionals required if known.
A team that works collaboratively, by communicating and sharing information, knowledge and skills	Space to describe: • Who is required to provide supports. • Why support is required for everyday activities across many settings.	Pre-populated text indicates a collaborative and coordinated team response is required. There is space to insert how and where families will learn to understand how to support their child's development.
Support required beyond individual discipline or unilateral response	Space to describe the input needed from more than one professional supporting one area of delay.	*No equivalent prompt to describe.*
Supports for an extended duration	Space to describe: • How long support is needed. • Settings support is required in. • Tools or assessments used to evidence the need for support over an extended duration. • Why support is needed for longer than 12 months.	*No equivalent prompt to describe.*

5.3.5.   How children are assessed against developmental delay criteria is subjective and uncertain

Children with developmental delay were originally intended to meet 'a high standard for children to be eligible' and satisfy a 'high access hurdle'.[930] This is because they are required to meet multiple criteria to satisfy the definition of developmental delay, as well as criteria for early intervention.

The eligibility criteria for developmental delay in the NDIS is almost exactly the same as that used in Victoria's Disability Act 2006 (replacing the Intellectually Disabled Persons' Services Act 1986). This presumably reflects that Victoria led the proposals to include developmental delay in the NDIS and raises an immediate question of whether it is fit for purpose within the NDIS given the definitions are almost identical. The compressed timeline between the Productivity Commission releasing its report in mid-2011 (which did not contemplate developmental delay) and the draft legislation in early 2013 suggests there was not sufficient time to test how this definition may be implemented within the NDIS as a key early intervention pathway.

Developmental delay requires a substantial reduction in functional capacity and need for a combination of interdisciplinary support over an extended duration (under section 9 of the NDIS Act). Meeting the early intervention requirements also means the CEO needs to be satisfied that supports are likely to benefit the person and that they can not be more appropriately supported outside of the NDIS (under section 25 of the NDIS Act).

However, this high bar has not eventuated in practice. There is no objective definition of substantial reduction in functional capacity or way to consistently measure a child's function. This means that there is still a degree of subjectivity and uncertainty in determining whether children have substantially reduced functional capacity.

> *"The NDIS criteria states that to qualify as having a developmental delay, a child's delay must have a 'substantial' impact on their functioning. However, it does not clarify what method is being used to determine something as having a 'substantial impact'. If clinicians knew that a client's difficulties were not likely to be considered substantial enough, they would not spend time and waste the NDIS's time with clients who would not qualify. I have worked with multiple clients that have experienced what I consider to be substantial language delays, but that the NDIS have said are not impacted enough, so they do not receive funding." - Provider[931]*

> *"There is no formal definition of what "SUBSTANTIAL" delay means. As individual clinicians, we all have different perceptions of what this is defined as. There is no numerical definition/age equivalent in NDIS guidelines to define substantial delay. We do not use standardised functional assessment tools to validate the extent of a developmental delay. Ages and Stages is a screening tool, that gives no age equivalent outcomes. Pedicat yields irrelevant results for children with DD [developmental delay]." – Provider[932]*

The ECEI Reset Project recommended the definitions of developmental delay and extended duration both be clarified. These changes were proposed to be implemented through Operational Guidelines and establishing thresholds to be tested through the introduction of Independent Assessments. While the Operational Guidelines have been updated, there remains a gap of how to consistently determine whether a child meets the eligibility criteria.

Since the ECEI Reset Project was completed the numbers of children accessing the NDIS with developmental delay have continued to rise. This suggests that updates to the Operational

Guidelines have not made it easier for Early Childhood Partners and access delegates to determine which children have the highest level of need.

Figure 64: Number of access decisions met for developmental delay each quarter [933]

5.3.6.   There if further pressure on access to the NDIS because of limited supports outside the NDIS

The lack of clarity on eligibility criteria is not the sole reason there are higher numbers of children accessing the NDIS. As described earlier in this section, the very limited amount of support available outside the NDIS has meant families have either had to fend alone without any support or seek access to the NDIS. It is not surprising that families seek access to get much needed support to ensure the very best outcomes for their children.

> *"Because there are so few services offered outside the NDIS, families are forced to push for access to the NDIS and maximum plan funding - even when that model might not lead to the best outcomes for their child." - Healthy Trajectories Child and Youth Disability Research Hub[934]*

> *"The NDIS offers quality supports to those who meet the criteria for the NDIS, however there are many children who miss out on funding due to lack of diagnosis or not meeting residency requirements. If a child has a developmental delay but not a diagnosis, there are limited options to receive therapy, particularly for families facing disadvantage who cannot afford private therapies. There are limited options for therapy and disability support outside of the NDIS which should be remedied to*

ensure all children have the opportunity to engage with school well." - The Hive Mt Druitt (United Way Australia)[935]

5.3.7. The use of Access Lists has resulted in an increased focus on diagnosis rather than function

Access Lists were created by the NDIA during the transition years to help participants likely to be eligible for the scheme gain access to support more quickly (see the Section 2.1.2 for more detail).

The Access Lists have inadvertently resulted in an increased focus on diagnosis rather than function and support need. This has meant children have often had to wait long periods without support to obtain a diagnosis and missed a critical window for intervention.

> *"It took over two years to get a diagnosis. During this time the distress to mother, child and family was debilitating and impacted all our lives emotionally, mentally, financially." – Child and Family Disability Alliance[936]*

It has also exacerbated inequality. Families able to pay for specialists are able to get a diagnosis more quickly, while those unable to pay are forced to sit on waiting lists. This can disproportionately impact those with lower socioeconomic status, Aboriginal and Torres Strait Islander and culturally and linguistically diverse families.

> *"My son was denied access at 5 years old as he had an adhd diagnosis and didn't meet disability requirements even though his functional capacity was well below that of his peers in all areas. I spent $5000 with money I didn't have for a ASD diagnosis and 2 months later he got in only because of his autism diagnosis. I was told by the planners to just change the date on the initial access form as everything else was still the same. How is that right?" – Carer[937]*

> *"The focus should be on addressing the individual needs of the child rather than solely concentrating on diagnosis. A significant financial burden is placed on families seeking diagnoses, especially in the case of children with Autism and those on the spectrum within migrant communities." – Utano Consulting[938]*

While the NDIS is supposed to be focused on function, in practice diagnosis has come to dominate the access process in large part due to the Access Lists.

> *"The scheme is meant to be a functional capacity needs-based scheme and not favour certain genetic conditions on the Operational Guidelines lists. These conditions-based lists should be abolished as access to the scheme and [sic] favours more common genetic conditions over rare ones." – Syndromes Without a Name (SWAN) Australia[939]*

> *"For example, under the NDIA initial assessment criteria, participants with Autism Spectrum Disorder (ASD) Level 1 diagnosis are ineligible to access the scheme. OTA is aware of situations where a participant has ASD Level 1 diagnosis and additional co-occurring disabilities that would meet the threshold for NDIA support when considered*

cumulatively based on their level of impact, and level of functional impairment,
however due to the presence of the ASD Level 1 diagnosis, participants NDIS
applications have been rejected outright." - Occupational Therapy Australia[940]

5.3.8.   Accessing the NDIS should be fairer and more consistent

We are proposing a package of reforms to the NDIS participant pathway. How children with developmental delay and disability access the NDIS is a key part of these reforms. The overarching approach to access is set out in Section 2.1.2. This section sets out changes that are specific to children under the age of 9.

The future access process should ensure there is support for families to make an access request. Eligibility should be focused on need and not simply diagnosis. Any information collected about a child's need should be used more consistently to inform decisions. The information collected will help the NDIA to build a better picture of the child's needs and circumstances and will be used to make sure that the service response best meets their needs.

These changes are needed to respond to the current inequity in access to the NDIS. Who the NDIS is for and how decisions are made about access should be clearer and decisions made more consistent.

There should be more support available outside the NDIS through foundational supports and mainstream, so children and families get the support they need (see Recommendations 1 and 2).

Figure 65: Overview of the four main areas of change proposed for access to the NDIS

1) Making the process of applying for NDIS access more transparent and simple	2) Clarifying definitions of key eligibility criteria in the NDIS Act	3) Standardised approaches to determine whether eligibility criteria is met
• This will require a new dynamic online Access Request and Supporting Evidence form and accompanying guidance. • The form should make clear what information is required and why. It should be responsive to information as it is entered and provide real-time guidance. • Additional enhancements to existing verbal or printed access request options should also be made	• This requires children under 9 to enter under section 25 (early intervention requirements) of the NDIS Act. • This requires a new definition of 'substantial developmental delay', and 'likely to benefit' for section 25 of the NDIS Act. • This requires clarification of the level of need that can and can't be met through foundational supports. • This should clarify who the NDIS is for and how decisions will be made.	• This requires assessment processes to be linked to the definitions in the previous column. • This requires developmental and behavioural evaluation assessments to link to developmental delay for sections 9 and 25 of the NDIS Act, and needs assessments to link to section 25 of the NDIS Act. • This should increase consistency in decisions and ensure the NDIS supports those with greatest need.

4) Removing automatic access under the Access Lists:

- This will require the NDIA removing automatic access through the Access Lists. This should be replaced with an approach of streamlining evidence requirements wherever possible to ensure only essential information is collected for all applicants seeking access.

- This should increase the equity of access to the NDIS once the additional changes outlined above have been introduced. These changes are required in order to remove automatic access. The current Access Lists should not be removed until the new approach is in place.

Making the process of applying for NDIS more transparent and simple

We are proposing a simpler and more guided process for making an access request for all applicants to the NDIS. This would be delivered through significant changes to how an access request is made, including revisions to the existing Access Request Form and Supporting Evidence Form, as well as what is currently used to collect evidence of developmental delay. The approach to revising the way access requests are made is set out in detail in Section 2.1.2.

A key change for children under the age of 9 and their families is that they will be supported by a Navigator to understand what the NDIS is, who it is for and how to make an access request. This is instead of Early Childhood Partners. Locally connected Navigators will be available to support

families to find and access supports across mainstream and foundational service systems and the NDIS (see Recommendation 4).

Clarifying definitions of key eligibility criteria in the NDIS Act

We propose that in the future all children under 9 should access the NDIS through section 25 (early intervention requirements) of the NDIS Act. We also propose that greater clarity be provided on some of the key eligibility criteria used for determining access to the NDIS. The criteria should be defined in a way that allows them to be linked to the outputs of an assessment process and allows comparison of applicants to their peers.

With all children entering through section 25 (early intervention requirements) of the NDIS Act in the future, there are two areas where an agreed definition is required that can be linked to an assessment process:

> 'Substantial developmental delay' is proposed to replace 'substantial reduction in functional capacity' in section 9 of the NDIS Act as part of the definition for developmental delay. This definition is linked to section 9 (definitions) and section 25(1)(a) (early intervention requirements) of the NDIS Act.
>
> 'Likely to benefit' in section 25(1)(b) and (c) (early intervention requirements) of the NDIS Act. This should be supported by clarification of the level of need that can (and cannot) be met through foundational supports in relation to section 25(3) (early intervention requirements) of the NDIS Act.

Children entering through section 25 (early intervention requirements)

Section 25 (early intervention requirements) of the NDIS Act is currently the most appropriate access pathway for children under 9 and their families. This is because access under early intervention criteria recognises early childhood as a significant period of growth and change and embeds a strengths-based model from the outset. It also simplifies the access pathway and reflects that all children ultimately enter the same early childhood approach once they are eligible.

This recommendation is also consistent with Recommendation 15 from the ECEI Reset Project. The project found that '…some parts of the Act may not be well-suited to young children. For example, the Act focuses on participant's goals and aspirations, which in an ECEI context, does not account for more holistic aspirations of the family. Best practice approaches recognise the importance of family capacity building delivered through a family-centred approach… [that the desired future state is] Children enter exclusively through s.25, with clearer focus on prevention and early support.'[941]

It also provides an opportunity to more clearly define the purpose of early intervention for all children, which should be to provide timely support to improve outcomes, build family capacity and enable genuine inclusion in community alongside their peers. Currently the NDIS is too narrowly focussed on individual therapy aimed at the child. Early intervention should aim to deliver genuine family-centred practice that builds family capacity to promote their child's inclusion and participation in typical childhood experiences.

"If the EC Approach is linked to delivery via a key worker model and family centred practice, where there is a strong focus on capacity building for families, then this can be followed up by providers with a sound knowledge of best practice. Such a strategy is going to lead to improved outcomes for children." – Carer[942]

"The Early Childhood approach needs to put more focus on the family unit when considering supports provided. The planning process should consider the best way, based on the broader circumstances of the family unit for the child with the disability to access the early intervention supports required. For example this may mean supports being provided to family members other than the child with the disability if that is the best way of supporting the child to access the supports required." – Down Syndrome Australia[943]

"A community raises a child not an individual." – Anonymous[944]

All children under 9 currently enter the early childhood approach which is a differentiated model from the rest of the NDIS. However, the access pathways and evidence requirements into the early childhood approach are different and confusing for families. Our proposed approach would simplify the access and evidence requirements by establishing a pathway specific to young children. It would provide a stronger link between the access decision and the supports the child and family receive.

Children with clear lifelong support needs would also enter through the early intervention pathway, but should be provided assurance by the NDIA that their eligibility would continue beyond age 9 under section 24 (disability requirements). Transfer to section 24 should in fact become a seamless and streamlined experience as the NDIA will have years of information about the child based on the previous access request, completed needs assessments and outcomes monitoring.

Importantly, the introduction of the needs assessment means that children will receive funding based on their need. This also means that any need for non-capacity building supports (such as core supports, assistive technology or equipment) will be identified and included in the reasonable and necessary budget. This is particularly important for children with the most complex needs and is a far more responsive approach than currently exists.

Defining substantial developmental delay

We are proposing to create a more consistent and equitable approach to eligibility. A key element of this is being clearer on what the eligibility criteria mean.

This will begin by testing existing developmental and behavioural evaluation assessments suitable for young children that adhere to best practice methods of child assessment. This will help to establish what works and what does not work. Once a suite of developmental and behavioural evaluation assessments have been tested, a definition will be established to make clear what a substantial developmental delay means. It is critical that a broad range of age appropriate domains is measured. The definition of substantial should be based on comparison of children to their peers so that the NDIS supports those with the highest needs (norm-referenced assessments). This uses a

norming-process to compare the results of the individual to their peers (this is described further in Section 2.1.2). The definition could then be operationalised through measuring standard deviations from the mean.

The Review is not proposing a definition. This needs to be done once the assessments have been tested and chosen. We do however suggest that a norm-based developmental assessment across age-appropriate domains is likely to provide the best framework for future evaluation. Work to determine the assessment process and the resulting definition must involve significant engagement and collaboration with families of children with developmental delay and disability, measurement experts and researchers, child development experts, and representative organisations.

The developmental evaluation should be able to differentiate between developmental concerns and lower need that could be appropriately supported by mainstream and foundational supports, and substantial developmental delay and higher needs that likely requires specialist supports from the NDIS.

These changes would provide greater clarity and transparency on eligibility for developmental delay.

> *"[A] potential solution [is to] outline specific criteria required to have a 'substantial delay', i.e. must fall below the 5th percentile in relevant standardised assessments, or must meet certain score in quality of life assessments, etc." – Provider[945]*

> *"[T]here needs to be a clear, consistent definition as to what "SUBSTANTIAL" delay means. Eg Something such as For Children over 2 years, a delay of 12 months or more, in developmental domains. For those under two, substantial delay could be defined as 6 months delayed. This would enable referrers to understand and interpret developmental delay NDIS criteria correctly and therefore guide the child to the most appropriate service. It would differentiate the DD [developmental delay] children requiring support through NDIS vs those with DD [developmental delay] most suited in other mainstream services. ECP's [Early childhood partners] need standardised, validation tools to assess function to ensure access pathway decisions are evidence based. Rather than an ECP [Early childhood partners] subjectively deciding if a child would be eligible, it makes sense to use standardised tools that would yield results that would guide the decision. E.g. A standardised developmental and behavioural evaluation assessment e.g. Brigance could be performed on all children to demonstrate the extent of a developmental delay. Substantial delay = NDIS, other delay = mainstream." – Provider[946]*

Likely to benefit and whether a person is appropriately supported by the NDIS

Children entering through section 25 (early intervention requirements) are also required to meet criteria that the CEO is satisfied that supports are likely to benefit the person and that they cannot be appropriately supported outside of the NDIS. This applies to children who are entering with

either a permanent impairment or developmental delay. The approach to clarifying these definitions is set out in detail in Section 2.1.1.

Similar to clarifying the definition of developmental delay, there also needs to be a clarification of these additional criteria that apply to all applicants under the early intervention pathway. This is because there will be some children who require support from the NDIS, but do not have developmental delay. Clarifying the additional criteria will make it clearer how these children will be assessed for access.

We propose linking the needs assessment to the existing criteria of 'likely to benefit' and whether the early intervention support for the person 'could be appropriately met' by mainstream or foundational supports. This should be clarified in the *NDIS (Becoming a Participant) Rules 2016*. The proposed needs assessment should provide a more consistent basis for the CEO to make a determination of benefit and whether support is more appropriately provided through foundational supports.

This would mean applicants accessing the NDIS through the early intervention pathway would not be deemed eligible until the CEO has determined they are likely to benefit from early intervention supports and that they have a level of support need that can't be met elsewhere and requires the NDIS. The needs assessment would make clear the level of need making it easier for the CEO to determine the appropriate service response. To be eligible there should be a clear theory of change that a period of early intervention funded by the NDIS would significantly improve outcomes and be cost effective. This theory of change should be tested through a needs assessment process.

Similar to the approach for development delay, the results of a needs assessment should be normed to compare the applicant against their peers. This requires that the needs assessment can generate a needs score, index or intensity level that can be compared. For example, the Support Intensity Scale for children generates a score for six domains that can be used to generate an overall Support Needs Index (see Section 2.2.2). This would ensure the NDIS is targeted towards those with the highest level of need. This is consistent with the original intent that "Tier 3 [NDIS] would be targeted at the much smaller group of people with significant care and support needs".[947]

Standardised approaches to determine whether eligibility criteria are met

We are proposing to use assessment processes to determine whether the key eligibility criteria described in the previous section have been met (see Section 5.3.8). This would be implemented by introducing a requirement for applicants to undergo a:

> Developmental and behavioural evaluation assessment and needs assessment for those under the age of 6 entering the NDIS through developmental delay as part of the early intervention requirements.
> Needs assessment for those entering the NDIS through permanent impairment as part of the early intervention requirements.

Figure 66 shows the link between the key eligibility criteria and approach of using assessments to determine whether key eligibility criteria have been met. These assessments would be paid for by

government and linked to the clarified definitions of the key eligibility criteria described in the previous section (see Section 5.3.8).

This will lead to a more equitable approach to accessing the NDIS by removing the focus on having a diagnosis and ensuring families don't have to pay for assessments to meet NDIA requirements. The cost of developmental and behavioural evaluation assessment should be met by government, ideally through Medicare. The needs assessment will be delivered by the NDIA and not have a cost for families.

Figure 66: Link between the relevant eligibility criteria and our proposed approach to use assessments to determine whether the criteria have been met

Specific access pathway	Key eligibility criteria	Relevant assessment
Section 25 (early intervention requirements): Applicant under the age of 6 with developmental delay	A. Substantial developmental delay	A. Developmental and behavioural evaluation assessment
	B. Likely to benefit from early intervention	B. Needs assessment
	C. Whether need for early intervention support can be met elsewhere	C. Needs assessment
Section 25 (early intervention requirements) of the NDIS Act: Applicant of any age who has an impairment that is, or is likely to be, permanent and is likely to benefit from early intervention	A. Likely to benefit from early intervention	A. Needs assessment
	B. Whether need for early intervention support can be met elsewhere	B. Needs assessment

These relevant assessments are described in order below.

Developmental and behavioural evaluation assessment

Children with developmental delay are required to undertake a developmental and behavioural evaluation assessment.

This assessment could be completed by a specialist who is trained and approved to use a particular assessment instrument. A specialist could only be approved to complete the assessment if they weren't also a provider of foundational or NDIS services. There should be no actual or potential conflict of interest for the specialist. An applicant may choose an assessor sourced by the NDIA if

needed. The cost of developmental and behavioural evaluation assessment should be met by government, ideally through Medicare.

In limited circumstances, the NDIA may request an additional assessment by another specialist or additional information to support a decision. The scenarios where this is and is not permitted should be included within the NDIS Rules.

The assessment and methodology should be designed to adopt a best practice approach for assessing child development, including observations, structured testing, parent questionnaires or interview and presentation across multiple settings (such as early childhood education and care or school). This includes taking into account existing data, reports and information from other individuals working with the child such as early childhood educators and teachers.

The developmental evaluation could be informed by a suite of developmental and behavioural evaluation tool(s) that can measure developmental and functional capacity across legislated domains. Existing assessments should be transparently tested with the groups and disability types they have been validated for, to inform the design of the future assessment processes.

These could include, for example, the Bayley Scales of Infant and Toddler Development, Vineland Adaptive Behaviour Scales and the Wechsler Preschool and Primary Scale of Intelligence.

Figure 67: Examples of case studies for existing assessments

Bayley Scales of Infant and Toddler Development	Vineland Adaptive Behaviour Scales	Wechsler Preschool and Primary Scale of Intelligence
• Extensive formal developmental and behavioural evaluation assessment tool for diagnosing developmental delays in early childhood. • It assesses five developmental domains - cognitive, language, motor, social emotional, and adaptive behaviour. • It is suitable for children aged 16 days to 42 months.[948]	• Standardised assessment tool used to measure adaptive behaviour skills for diagnosing intellectual and developmental disabilities, autism and developmental delays. • It measures adaptive behaviour across communication, daily living skills and socialisation. • Suitable for children and young adults up to 18 years. It is suitable from 3 years old to adult.[949]	• An intelligence (IQ) test that provides 15 subtests (categorised into core, supplemental and optional) composite scores representing intellectual functioning in verbal and performance cognitive domains. • Measures cognitive development for pre-schoolers and young children. • Suitable for children aged 2 years and 6 months to 7 years and 7 months.[950]

There needs to be work undertaken to identify, test, refine and validate the suite of developmental and behavioural evaluation assessments. The suite of tools must be valid for various ages and groups, children from culturally and linguistically diverse backgrounds, children showing early signs

of autism and children with complex communication needs. A specific suite of tools should be designed with Aboriginal and Torres Strait Islander communities. Any assessment should cover a broad range of age appropriate domains in order to be strongly considered for use.

This will require the NDIS Experience Design Office to work with (at least but not limited to the following): children and families, measurement experts and researchers, child development experts, and representative organisations.

The suite of tool(s) will need to:

- Be linked to the agreed definition of substantial developmental delay.
- Be norm-referenced to measure developmental delay in a way that allows children to be compared to their peers.
- Collect the minimum evidence on level of delay to satisfy a delegate that requirements have been met.
- Map to the World Health Organisation International Classification of Functioning, Disability and Health to enable consistency of data collection and tracking of outcomes across service systems.
- Be able to be undertaken by specialist, who is trained and accredited in the use of the assessment.
- Be designed with and acceptable to the people and groups it is used to assess.

The outcomes of the assessment will be considered alongside the self-reported information and other evidence from the treating professional to assist the NDIA Needs Assessor in making an access decision. An applicant would still need to meet other relevant eligibility criteria in order to access the NDIS through section 25 (early intervention requirements) of the NDIS Act.

Needs assessment (for informing an early intervention access decision)

Applicants of any age who are entering under early intervention will be required to undertake a needs assessment. This includes children entering under developmental delay. The approach to using a needs assessment to inform an early intervention access decision is set out in Section 2.2.2.

The needs assessment would be the final step in the process. An applicant would only become eligible for a needs assessment once they have already satisfied the remaining eligibility criteria for access. That is, the delegate would be satisfied that all other criteria have been met and believe it is appropriate for the applicant to move onto a needs assessment. At this point, a person would have been required to undertake a needs assessment to determine the budget anyway.

This will strengthen the link between need and access to specialist supports in the NDIS. It will ensure children and families receive the right supports at the right time. Completing a needs assessment will provide a much stronger referral pathway for children who aren't eligible for the NDIS, particularly with foundational supports including a greatly expanded offering of early supports and family capacity building.

This could include a period of Lead Practitioner support, referral to peer support or family capacity building services. This could allow families of children with lower levels of need to build their capacity and connections to community prior to engaging in specialist disability services.

Removing automatic access to the NDIS under Access Lists

In addition to the above, we are proposing removing automatic access to the NDIS under Access Lists. Automatic access should be replaced by a principle of streamlining evidence requirements wherever possible to ensure only essential information is collected for all applicants seeking access.

The approach to Access Lists is set out in Section 2.1.2.

5.3.9. Case studies demonstrate how the revised access should work

The case studies below provide further detail on how the changes described above will work in practice. The case studies highlight differences between how the current pathway works and how the future process will work for children:

> **Case study 13: Malik, 3 years old, male, developmental delay, section 25 (early intervention requirements) access request**
>
> Amira and Kareem are young parents and Malik is their first child. Malik loves stories and going to the zoo. His favourite animal is the meerkat.
>
> His childcare educators have just arranged a meeting with Amira and Kareem to talk about Malik's development. Malik is not making eye contact, cannot feed himself and has more difficulty settling and participating in activities compared to his peers.
>
> Amira and Kareem are concerned, but also relieved. They have been worried about Malik at home as he is not feeding well, has difficulty sleeping and struggles to communicate his needs and wants.
>
> The educator suggests that Malik needs additional help and that they should look into some additional supports from the community and the NDIS. Amira and Kareem go home and look into the NDIS more online.
>
> Current access pathway
>
> - Amira can't find the information she is looking for on the NDIS website, so she calls the 1800 number. The National Contact Centre gives her the number for her local Early Childhood Partner.
> - Amira phones the Early Childhood Partner to ask whether Malik is able to get more support.
> - Sarah, who works for Early Childhood Partner asks a few questions and Amira tells her about the concerns they have about Malik's development and what the educators have said. She says the next step is for someone at the Early Childhood Partner to observe Malik in-person and to bring along any reports or forms she has about him.
> - Amira books in the next available appointment for Malik, which is six weeks away. A few days later a generic email is sent to the family with some information on child development and a

list of services and supports available in their local community. Amira and Kareem read the email but don't really understand the information or what to do next.

- Sarah rings Amira and Kareem the day before the meeting. She wants to change the appointment to a Microsoft Teams call because she is in back-to-back meetings. Kareem and Amira aren't sure but agree because they don't want to put the appointment back further. During the video conference Sarah completes PEDI-CAT and Ages and Stages Questionnaires (ASQ) with the family. Malik's results on the ASQ indicate further assessment with a professional is warranted.

- After the session, Sarah contacts the educators at Malik's day care. They confirm some of the difficulties Malik is experiencing.

- Sarah completes the Evidence of Developmental Delay form. She arranges another meeting with the family to complete a Verbal Access Request on Malik's behalf. The call with the Access team takes 1.5 hours and covers a lot of the same questions they've already told Sarah. Three weeks later they receive a letter confirming Malik is eligible for NDIS support under developmental delay.

- Malik and his family are contacted by the Early Childhood Partner to book in for a planning meeting. Kareem and Amira are yet to connect in with any support and are unsure what a planning meeting is.

Future access pathway

- Malik's family find their local Navigator, Clancy, by looking online. They talk to Clancy about their conversation with the educators and the concerns they have for Malik's development.

- Clancy suggests a starting place could be a local family capacity building program that helps families set goals and priorities. After finding out more about Amira and Kareem he does some more digging in his system and finds an online peer support program where they can speak to other families of children with developmental concerns in Arabic. His final suggestion is a residential sleep and settling program that is further from their house but is closer to Amira's workplace.

- He explains the early childhood approach and what support might be available. With consent, Clancy helps Amira and Kareem to initiate an access request for Malik. The information they have from the early childhood educator is enough to proceed to the developmental and behavioural evaluation assessment stage.

- Clancy talks about the developmental and behavioural evaluation assessment that is required for children who might have developmental delay, and searches the approved assessor list for Amira and Kareem. They are excited to find out that Malik's GP (George) is trained and approved to complete an assessment.

- Amira books a long appointment with their regular GP. George is able to easily establish rapport with the family given their history and works with Malik and his family to complete the Bayley Scales of Infant and Toddler Development. George also phones the early childhood educator to discuss Malik's development. The assessment is covered through Medicare and the family doesn't need to pay out of pocket.

- The results of the assessment show that Malik has a substantial delay in both language and social-emotional development.
- Clancy follows up with Amira about the results of the assessment. The results have been uploaded automatically to the access portal. They add some remaining details into the initial section of the access request and receive confirmation that Malik is eligible for a needs assessment as the final step. He explains that the needs assessment will help to determine what type and level of support Malik requires. If that can't be met by foundational supports, he'll receive funding in his NDIS budget to access additional supports.
- Malik is matched to a skilled NDIA Needs Assessor called Lucy who is a speech therapist. With Kareem's consent, she receives the results of the developmental and behavioural evaluation assessment and notes from George, including his conversation with the educators.
- Lucy contacts Amira who asks for the needs assessment to be done at their family home where Malik is most comfortable. Lucy asks about Malik's interests and asks if there are any adjustments Malik might need for the visit. Amira mentions Malik's interests in animals and meerkats but doesn't ask for any adjustments.
- Lucy mentions she has a social story that she can email through to help Malik understand who she is and why she is visiting, which Amira agrees would be helpful.
- Lucy reviews the information on Malik's file and prepares detailed notes on the gaps and where she should start the needs assessment.
- Lucy packs a game with meerkats and brings a number of books about animals. Malik is shy at first but is interested in the meerkat game and gradually comes closer to Lucy. Lucy observes Malik through play and while he is eating his lunch. She has detailed conversations with Amira and Kareem, including about their wellbeing and how they are supporting Malik to manage his emotions.
- Back at the office, Lucy consults with her colleagues to ensure that she is appropriately assessing the holistic impact of Malik's developmental delay.
- Lucy returns to Malik's home for the second assessment session, and shares with Amira and Kareem how she has assessed Malik's need so far across each domain. She checks her notes and assumptions with them and provides them with a copy.
- The assessment reveals that Malik's needs are very high compared to his peers and he is likely to need an extended period of specialist support from a transdisciplinary team. Based on his age and need, Lucy determines that Malik is likely to benefit from at least two years of early intervention support covering communication, social and self-care skills. She recommends that another needs assessment is done in six months because of his age and recent access to the NDIS.

Case study 14: Ella, 8 years old, cerebral palsy, section 25 (early intervention requirements)

Ella is a funny and charming 8 year old girl with curly brown hair who loves to sing and perform with her friends from school. Ella is the first child of James and Gill.

At around six months old, Ella was diagnosed with cerebral palsy and scored Level 3 on the Gross Motor Functional Capacity Score. When Gill and James received Ella's diagnosis, the hospital social worker advised Gill and James to contact the NDIS.

Current access pathway

- Gill accesses the NDIS website, downloads an application form and answers a series of questions to provide information about Ella's disability/diagnosis. She follows the instructions to contact her local Early Childhood Partner before submitting the paperwork, but someone at reception tells her to apply directly with a copy of Ella's diagnosis of cerebral palsy.
- After three weeks, Gill receives a letter in the mail saying that Ella has met access under the disability requirements. She doesn't understand what this means.
- Gill receives a number of phone calls from an unknown number who doesn't leave a message. When she answers the call it is from an Early Childhood Partner, Mary, who wants to schedule a planning meeting. Gill and James are not sure what this means but agree to book an appointment.
- In the planning meeting, Mary asks lots of questions about what Ella can and can't do which makes Gill and James sad and uncomfortable. Mary also asks what kind of goals they have for Ella, which is something they hadn't really thought about before. Mary suggests some broad goals which they agree to include in Ella's plan.
- Three weeks later Gill and James receive a letter in the mail saying that Ella's plan has been approved. There is reference to a baby named Shaun in the "About me" section which confuses Gill and James, and they are unsure about what the next steps might be.
- Mary calls the next day to tell Gill and James the plan has been approved and lets them know the amount of funding that has been approved for Ella. Gill asks what Capacity Building means and Mary says it's for therapy supports like a Physiotherapist to help Ella reach the goals set out in her plan. Gill asks about the baby, Shaun, in the About me section and Mary says she will look into it.
- Gill asks if she can recommend anyone, but Mary says she can't make recommendations. She sends Gill an email that includes a list of local therapy providers. When Gill rings a number of providers, she finds that they all have a long waiting lists or are not taking any new clients. Some of the phone numbers aren't even connected.
- They're not sure what to do next and start searching through Facebook groups to see if they can get help from other families.

Future access pathway

- Gill's GP explains where the office of the local Navigator is. Gill drops in and is matched with Leonie who explains the early childhood approach to her. With Leonie's help, Gill completes a NDIS access request online and sends a link to Ella's Pediatrician for input. The link allows

- Ella's Pediatrician to enter the information directly into the access portal which includes guidance on what is needed and what terms mean.
- Leonie also lets Gill know that an inclusive parents and bubs playgroup has just started up in Gill's suburb, she encourages Gill to join the group to support Ella's development. A physiotherapist drops in once per month at the playgroup and is able to review Ella's development. Leonie also tells Gill about an upcoming workshop being run by the local cerebral palsy organisation where she might like to connect with other families.
- Based on the contact details and preferences in Ella's application, Gill receives a phone call from Shane, an NDIA Needs Assessor. Shane is a Physiotherapist, and he makes a time to meet with Gill and Ella in the family home. They are keen to do a single longer assessment and have it over and done with.
- Before the meeting, Shane reads all the information Gill has already provided through the application process and he reviews the latest research on interventions for children with cerebral palsy. He calls the central assessor team to speak to the NDIA cerebral palsy expert who gives him a briefing on things to ask and suggestions for how to run the assessment. He suggests giving him a call back after the assessment to test his thinking.
- During the assessment, Shane spends several hours talking with Gill and James and time playing with Ella. With consent, he contacts Ella's Pediatrician to find out more. He also calls back his colleague in the central assessor team as he wanted to test this thinking about a few ideas for Ella's support needs.
- He recommends that she would benefit from a period of at least five years of early intervention to support her physical and communication skills. Shane knows that Ella's needs will be regularly evolving and ensures that the needs assessment accounts for expected growth and development, as well as equipment costs. Regular informal and more formal case conferencing sessions are also provided for, where a needs reassessment can be initiated should Ella's needs change significantly.
- Given that Ella will need significant support with her physical development, Leonie talks to Gill about the benefits of working with a Lead Practitioner and the process to request this support. Gill makes the request for a Lead Practitioner with a Physiotherapy background and is subsequently matched with Kristine (for more detail on Lead Practitioners read the sections below).
- After four years of intervention, Gill and James decide to repeat Ella's Gross Motor Functional Capacity Score, and she scores a Level 3. Ella's Pediatrician explains this means Ella is likely to need a walking aid inside and manual wheelchair outside the home into adulthood. When discussing this with Kristine, Gill learns that this means that Ella will likely meet disability criteria when she is 9 years old. This means that Ella will likely need support from the NDIS for the rest of her life.
- Over the next three years, Gill and James do a wonderful job building a valued and included life for Ella. Ella participates in typical childhood experiences like Little Athletics where she sets a new personal best in her wheelchair and Nippers where she loves to catch waves with her friend's brother who does water safety for their age group.

- Kristine has continued to coordinate a team of providers around the family, supporting them to build Ella's capacity during their daily routines, and ensuring that Ella has had the right equipment and level of support to get around, play and learn in kindergarten and then school. Gill and James feel well supported, have regular date nights and are thinking of a sibling for Ella.
- When Ella is turning 8, they receive a letter in the mail from the NDIA that says that they don't need any more information about Ella to transition to section 24 (disability requirements). It says that they are able to use the previous needs assessments and Gross Motor Functional Capacity Score as evidence. This gives them comfort that she will continue to be supported as she gets older.

5.3.10. Action & Implementation Details

Action 6.2: The National Disability Insurance Agency should reform the pathway for all children under the age of 9 to enter the NDIS under early intervention requirements.

This should include an agreed definition of 'likely to benefit', and clarification of when need can be appropriately met through the reformed foundational supports system (that is, linked to the outputs of a needs assessment - see Action 3.4). These should be clarified in the NDIS Rules. Children with clear lifelong support needs should also enter through the early intervention pathway, but should be provided assurance by the NDIA that their eligibility would continue beyond age 9 under section 24 (disability requirements). Existing access lists should be removed and automatic access replaced with streamlined evidence requirements to ensure only essential information is collected. Additional evidence required by the NDIA to inform complex access decisions should be funded by government.

Implementation detail:

- As part of implementing the broader reforms to the NDIS early intervention pathway (see Action 3.7), the NDIS Experience Design Office should ensure that adjustments to the pathway are appropriate for children under the age of 9 and their families. The pathway should include:

  - An access process that includes the new approach to assessing developmental delay (see Action 6.3 below) for children where this is relevant.

  - An access process that uses a needs assessment to inform the CEOs determination of whether a person:

    o Is likely to benefit from early intervention (s25(1)(b) and (c) of NDIS Act).
    o Could have their needs met through the reformed foundational supports system (s25(3)).

- Budget setting based on evidence of the frequency, intensity and type of supports that are appropriate for children based on their needs assessment (see Action 6.4). The frequency of re-assessment of need should be conducted biennially or at a frequency determined by the Needs Assessor at the preceding assessment (reflecting the context and circumstances of the individual).

- Support for the participant and family from a Lead Practitioner and Navigator to develop a plan of action to use reasonable and necessary funding to access and adapt supports and combinations of supports that work for them. This should also involve regularly scheduled check-ins and mechanisms such as case conferencing to discuss the individual's progress and adjust the approach where expected benefits are not being delivered (see Action 6.6).

- The NDIS Experience Design Office (see Action 24.3) should ensure that:

  - The responsive access request process (see Action 3.2) can provide the necessary guidance to applicants and functionality to support the pathway described above.

  - The development of the needs assessment (see Action 3.4) can provide the functionality described above and includes consideration of the need for a distinct approach for young children and to identify support needs for young children.

  - The design of the Navigator and Specialist Navigator functions (see Action 4.1) and Lead Practitioner role (see Action 6.5) can provide the functions described above, including an approach for Navigators to be involved in the regular monitoring of the effectiveness of early intervention supports alongside Lead Practitioners (see Action 6.6).

- The Department of Social Services should develop and bring forward proposed amendments to the NDIS Act and Rules to enable the implementation of the proposed changes described in Actions 6.2, 6.3, 6.4, 6.5 and 6.6. Amendments should be developed once the assessment processes and definitions for the relevant eligibility criteria have been established and endorsed by Disability Reform Ministers.

- The National Disability Insurance Agency should establish a dedicated workforce who are appropriately trained and skilled to support the pathway for children. They should be equipped to make more consistent and equitable access and eligibility decisions. This workforce should be trained in understanding and identifying what constitutes best practice and evidence-based supports for children that are family-centred and delivered in natural settings.

- The NDIS Evidence Committee (see Action 23.2) should provide advice to Disability Reform Ministers and the NDIA on effective early intervention practice and the early intervention supports and intensities that are likely to be beneficial (or not) for children. This should inform access and budget setting decisions and practice guides for early

intervention. This includes clarifying what are reasonable and necessary supports for children.

- The NDIA should begin implementation of the reformed early intervention pathway for children, including all relevant assessments once Disability Reform Ministers have endorsed the process, tool(s) and proposed implementation approach.
- The NDIA should develop a comprehensive suite of resources and information to support community and family understanding of the early childhood intervention pathway.

Action 6.3: The National Disability Insurance Agency should introduce a more consistent and robust approach to assessing developmental delay.

This should include a precise definition of substantial developmental delay to give more clarity to applicants and consistency in decision-making, replacing the current test of substantially reduced functional capacity. This definition should be linked to the outputs of a developmental assessment that can determine children's developmental functioning and allow applicants to be compared to their peers (norm-referenced assessments). The definition could then be operationalised through measuring standard deviations from the mean.

This would require a suite of developmental and behavioural evaluation assessments suitable for young children that adhere to best practice methods of child assessment. Existing developmental assessments should be transparently tested to inform the design of the new process. Any assessment should cover a broad range of age appropriate domains in order to be strongly considered for use. Any assessment considered should take into account that delay and disability can fluctuate over time, and based on the environments in which a person is in. There should be an accepted basis for comparing results from two or more acceptable instruments that might be used to assess delay in a given domain.

This assessment should be made universally available through the health system to be completed by a trained specialist who does not have a conflict of interest.

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should design and test a standardised assessment process to determine the extent of developmental delay for the purpose of informing access decisions. The assessment process should have the following features:

  - Be a customised suite of developmental and behavioural evaluations suitable for assessing young children. The assessment should be designed through a transparent process that begins with testing existing validated instruments for this specific use.

The design process must include (but not be limited to) families of children with developmental delay and disability, measurement experts, health professionals, and representative organisations. The assessment(s) should:

- o Be norm-referenced to measure development delay in a way that allows applicants to be compared to the population.
- o Collect the minimum evidence on extent of delay to satisfy a delegate that access requirements have been met.
- o Be able to produce scores that quantify the extent of delay in self-care, receptive and expressive language, cognitive development and motor development.
- o Be able to be undertaken by an applicant's treating professional, if they are trained and accredited in the use of the assessment, or an NDIA-funded trained and accredited Needs Assessor in cases where an applicant does not have an existing treating professional available.
- o Be designed with and acceptable to families of children with disability and their representative organisations.

- There should be a mechanism for monitoring the assessments undertaken by treating professionals to identify where an individual may be improperly completing assessments and to bar the individual from completing further assessments for the purpose of providing evidence to the NDIS.

- The National Disability Insurance Agency should begin implementation of the developmental evaluation once:

  - Australian Governments have agreed to the use of development delay as an eligibility criteria and legislation has been updated.

  - Disability Reform Ministers have endorsed the assessment process and proposed implementation approach.

5.4. There should be increased investment in getting the budget right for children and families and more support to use funding

Many families find planning processes are confusing, stressful and disempowering. Planning is not family centred and families do not feel well supported. They feel they are wasting time and money collecting reports that are not read, and the must paint the worst picture of their child and their family in order to justify requests for support. Decisions do not appear to reflect their child's needs despite the wealth of information provided.

Once a plan has been set, we have heard there is limited support to help understand and use funding. Capacity building supports have restrictions on how the funding can be used. This prevents families finding innovative ways to meet need.

We believe the approach to budget setting and planning should be consistently needs-based – from how budgets are determined through to how those budgets are implemented. Funding

should be based on need and ensure that children with similar levels of need and in similar circumstances receive similar budgets. Once a budget has been determined, families should get more help in finding and choosing services and supports that will work best for their child.

These proposed reforms are closely linked to a revised approach for all participants to setting budgets and supporting participants to use their funding. The detail of those reforms are set out in Section 2.2.2. This section is focused on budget setting and planning for those who are younger than 9. The intent and principles of this approach is consistent for applicants and participants under and over the age of 9.

5.4.1. Planning for children is adversarial and there is little support for families

Issues with the current approach to how plans are developed and how families are supported to implement their child's plans has meant the NDIS has not been consistently needs-based.

Families find planning confusing, stressful and disempowering. They feel they must present their child in the worst possible light to receive support. Funding outcomes are inconsistent and too often determined by the ability of the family to advocate. Decisions are often made by someone who has never met the child or family.

The concept of parental responsibility makes it even more confusing for families to understand what the NDIS can (and cannot) fund. Lack of clarity around what the NDIA considers reasonable and necessary creates conflict between families, professionals, Early Childhood Partners and NDIA staff when requested supports are not provided. It is not clear to families how or why the NDIA makes decisions on individual supports.

There is little support for families to understand and implement plans. There is almost no support for families to understand what is likely to get the best outcomes for their child.

A significant change is needed to more effectively support children and families.

The current planning process

The current approach and challenges of planning reflect many of those outlined for all participants. See Section 2.2.1 for more detail on these broader challenges.

Despite this, the experience of children and families is still distinct. Families of children who have been newly diagnosed are frequently at the beginning of their disability journey and can be confused about where to start or what is possible. Families who have been through developmental assessments can already be well linked into allied health supports and may bring more information or evidence to the planning process.

Families prepare for planning meetings by beginning to collect information often well in advance of the meeting. Some families use peer or representative organisation resources to help them prepare. Other families may complete the early childhood approach booklet supplied by the NDIA. Others walk into their first meeting with little or no information about what their child might need or even what the meeting will entail. There is no consistent approach or level of information being

brought to each planning meeting. What is consistent is the recommendations of health or allied health care teams are heavily weighted by most families during this time.

Families will then meet with either an Early Childhood Partner or a NDIA planner to hold a planning conversation and begin building a plan. The conversation aims to identify the child and family's goals and aspirations, support needs and what community, mainstream and funded supports might be required. It will also include completion of guided planning questions, the severity tool, outcomes and family questionnaire, risk assessment and a functional assessment using PEDI-CAT. The plan will be built after this planning conversation.

- For children younger than 6, a Practice Guide is a resource that can be used to determine the plan funding level following a structured approach. The intent of the Practice Guide is to fund a model that enables the delivery of best practice.
- For children aged 7 or 8, the process is the same as used for adult planning sessions (see Section 2.2.1). Where the primary disability, severity indicator, responses to the guided planning questions and outcomes questionnaire will be used to generate a Typical Support Package and the planner builds up support items for the support budgets. Further details on Typical Support Packages and its drawbacks are set out in Section 2.2.1.

A delegate will determine whether the support items are reasonable and necessary and decide to approve or not approve the supports. Families of children younger than 9 are far more likely to have their planning conversation with an Early Childhood Partner. This means that the approver is likely to be a delegate who has never met the family. This is challenging for families and Early Childhood Partners alike. Families are frustrated by an unknown person making decisions that aren't transparent or well explained. Early Childhood Partners have told us they feel caught in the middle of the expectations of families on one hand and NDIA priorities on the other.

Planners often need to weigh up a significant amount of information supplied by families. The functional assessment may or may not help decisions, given that there is not a one-to-one relationship between function and support need. Decisions must be made within the highly complex policy and legislative framework for resource allocation, including the reasonable and necessary test (see Section 2.2.1 for further detail on challenges with reasonable and necessary). It is a complex task for planners.

The current approach and support for plan implementation

After delegate approval, a plan is sent to families. It follows the same format with the same budget categories as provided to adolescents and adults in the scheme (a copy of the plan is included in Section 2.2.1).

Most plans for children are made up of Capacity Building line items, usually in the Improved Daily Living Skills support category. The comments included in the plan to describe the support are kept at a high level to promote flexibility. But the lack of explanation can cause confusion for families. How the funding was calculated is not transparently or simply explained.

The NDIA has developed several fact sheets to help families use their plans. These include "how to select a provider", "what is best practice" and "what is a key worker". But these are only available on the internal intranet. Access to this information relies on the Early Childhood Partner or planner bringing it up in the plan implementation meeting or proactively supplying it to families via email.

Early Childhood Partners or Support Coordinators can provide plan implementation support. But we have heard that many families need more assistance than what is made available. Competing priorities means that Early Childhood Partners have limited time to assist with plan implementation. Few families are provided funding for Support Coordination, with the NDIA considering that to be the role of a key worker. Yet the key worker role is not readily understood or widely available in the market.

Key issues with these processes and approaches

Figure 68: Key issues with the current approach include:

1) How plans are set and reviewed	Issues include: • A resource intensive and ineffective information gathering process. • A stressful, deficit based planning process • Planning meetings that feel more like a budget negotiation. • An inequitable approach to budget setting that is not well matched to child or family need and does not incentivise a best practice approach.
2) How families are allowed and supported to implement their plans	• Complex and inflexible plans • Insufficient support for children and families to use their budgets to get the best outcomes.

The following sections provide more detail on each of these issues.

Issues with how plans are set and reviewed

The challenge of reasonable and necessary and parental responsibility

Many of the issues with planning in the NDIS stem from the undefined concept of reasonable and necessary. This applies equally to children and families and older participants. General challenges with reasonable and necessary are set out in detail in the Section 2.2.1.

We have heard families face additional specific issues with reasonable and necessary. This includes the dominant focus on support for the child as well as the concept of parental responsibility.

> *"I hate hearing the words parental responsibility because our parental responsibility is a lot different to someone that has a typical child." – Parent[951]*

"the whole thing around parental responsibility needs to change." – Parent[952]

"After each planning meeting I am left in tears and feel extremely stressed. The planners are generally rude, lack empathy and have limited (if any) understanding of disability. Please employ people with lived experience of disability. Please adequately train staff." – Carer[953]

Families have told us about their frustration that planners don't take a holistic approach to understanding the needs of the whole family. This is particularly the case when there are multiple children in a family, or multiple family members in the NDIS or circumstances where there are limited informal supports available, such as single parents . There is also a lack of a holistic approach for Aboriginal and Torres Strait Islander families.

Understanding can be improved where families provide a carer or family impact statement, but this is not required, and less likely to be provided by families who may have more difficulty navigating complex service systems. This is not consistent with an approach based on best practice principles which should seek to truly understand and support the uniqueness and strengths of individual families and all of their children.

"Affirm that the wellbeing of children is dependent on the wellbeing of the family system, and vice versa. This means: Providing coordinated supports and services at the family system level, rather than just for individual children, and allowing coordinated supports where multiple children within a family are NDIS participants." – Australian Psychological Society[954]

"The importance of wrap around and indirect supports for families must also be acknowledged in building capacity in families, reducing their stress and improving outcomes for their child. However, as identified within the What We Have Heard Report, the NDIS is confusing and overwhelming. Families need support to navigate the system, and assistance in coordinating their supports. These supports are currently limited, often putting pressure upon therapy providers and increasing their burden of care to support families. These services are more appropriately provided by support coordinators and/case managers. These types of providers are an important support for families, particularly in the early stages of their child's involvement with the scheme and should be funded automatically." – Speech Pathology Australia[955]

"AMPARO works with many single parent families, some of whom have more than one child with a disability, often with significant support needs. These families report they are unable to undertake essential and routine activities such as grocery shopping, going to medical appointments, during the holiday period. Because of this some children are looking after their siblings with disability, just so that their parent can do the basic food shopping. Whilst many school age children attend Vacation Care Programs, some children with disability are not accepted into these programs, as their

needs for one-on-one support are considered beyond their scope. Going out as a family during this period can be impossible." – AMPARO Advocacy[956]

"…the transformative power of family support cannot be understated. When we invest in bolstering families and unpaid carers, we're planting seeds for a brighter future for the child with disabilities. Such support alleviates immediate pressures and challenges, paving the way for improved long-term outcomes for the child. We can also create a proactive defence against future health and social care costs by mitigating stress and potential health complications within families." – Lifely[957]

One of the biggest areas of contention is the concept of 'parental responsibility'. Reasonable and necessary supports must consider what is reasonable for informal supports like family or friends to provide. For children under 18, the NDIA considers that it is reasonable for families to provide substantial care and support for their children.[958] For younger children, this is typically all care and support and as children age the amount of care and support provided by families typically reduces.[959] However, the *NDIS (Supports for Participants) Rules 2016* includes three tests to determine what is reasonable for informal supports to provide.[960] These include whether the child's care needs are substantially greater than other children of a similar age because of their disability, any risks to the wellbeing of the informal supports and whether the provision of NDIS funding will help build the capacity of informal supports or reduce risks to the child. The NDIA also considers whether the support is most appropriately provided by the NDIS or another service system, such as early childhood education and care or the school system.

Making a decision about parental responsibility is a complex task for a delegate, particularly when they have not met the child or family. They are required to consider multiple elements in making a decision. Some of the challenges operationalising the concept in a consistent and transparent way include:

- An imbalance in knowledge, with internal practice guidance providing far more detail to decision makers on these concepts than what is publicly available for families.
- At the same time, no guidance appears to be provided to delegates on what is typical for child development.
- A high standard of evidence is required to substantiate the need for any core supports, such as creating a timetable of the child's and family's routine.

The Independent Advisory Council provided advice to the NDIA on the reasonable expectations of informal support and the challenge of parental responsibility in their Reasonable and Necessary support across the Lifespan: An Ordinary Life for People with Disability Report. For children from birth to 5 years, they envisaged that families would be encouraged to use informal care such as grandparents, friends and babysitters. They also envisaged inclusion in playgroups and early childhood education and care settings would be encouraged. Both of these concepts are consistent with best practice principles around inclusion and building the capacity of important people in a child's life. They also indicated that it would be reasonable and necessary to include support for

families to facilitate a functioning family. Where there were vulnerabilities, reasonable and necessary funding would include 'whatever it takes' to facilitate a healthy well-functioning family.[961]

Despite the Independent Advisory Council's advice, problems persist. Families believe that the term 'parental responsibility' is being used bluntly to avoid funding any core supports. Supports that would strengthen the sustainability of informal supports from families are not being funded consistently. Children younger than 9 are far less likely to have flexible core supports in their budgets, with around three-quarters of annual funding for young children being allocated for capacity building supports as of 30 June 2023.[962] This is despite the evidence that supporting the development of positive and responsive caregiving relationships should be a major priority of early intervention.[963]

> *"The fact that parental responsibility is consistently used as a means to not fund supports when a child without the same needs would not need such parent input and support to live a normal life. The fact that these people make parents/carers of and people with disabilities to feel like criminals just to get basic needs and supports." – Parent[964]*

> *"It's not just... in one particular thing or area that our child might need extra support, and it's over multiple different areas, often all at the same time, which is so overwhelming and a lot more than what a typical child would need... It feels like kind of like you're being a bit gas lit when someone says something like that to you that your reality just isn't true." – Parent[965]*

> *"I'm not eligible for travel or anything like that, because it falls under parental responsibility and like, I've never had this responsibility with any of my other kids where I've had to go to appointments 3 times a week, you know an hour away, so that whole parental responsibility thing is just I think that's a load of rubbish." – Parent[966]*

Lack of clarity and contest over the concepts of reasonable and necessary and parental responsibility combined with a lack of transparency about how and why the NDIA make the decisions has resulted in ongoing conflict between families, providers, Early Childhood Partners and the NDIA. There can sometimes be a gap between requested supports and what is considered best practice or what the NDIS can sustainably provide.

> *"Supports should not be denied based on "parental responsibility" where supports are required due to disability. All supports should be relationship based and parent led... Early intervention should be recognised as a valuable investment in the future of these children, and should be given funding priority as this can lead to significantly better quality of life as these children grow into adults, and greater likelihood that the needs of these individuals will reduce as they become adults rather than the current system of neglect leading to adults who require full-time care." – Carer[967]*

Collecting evidence to substantiate need

As described in Section 4.1.1, the NDIA has responded to the challenge of difficulty in decision-making by requiring greater levels of evidence and increasing the burden of proof on the families. This has made proving a support is reasonable and necessary an expensive and intensive exercise.

We have heard that families often spend significant time and resources completing assessments and collecting reports about their child. Families feel that they need to produce evidence that proves a certain level of funding is necessary to have any chance of the NDIA agreeing to fund a support. This results in reports being gathered that recommend a specific type and number of therapy hours and reinforces the approach that the child needs specialists. This focus on increasing therapy hours does not guide families to best practice approaches.

Families feel compelled to provide multiple reports to justify budgets and often spend a significant amount of the plan on reports. Many believe this effort is wasted when the approved plans do not reflect what is recommended by professionals who have met and assessed their child. There is a strong belief that reports are not being read before planning meetings and that planners often disregard the recommendations when making decisions.

Family members told us that it would be much easier for the NDIA to be explicit about requirements to avoid the significant time and money spent on external reports and assessments.[968]

> *"…for it to be compulsory, that they read all the evidence and reports that we provide. I spent 6 months last year sourcing reports, 24/7 spreadsheets of care needs for the week. 2 care impact statements, support worker statements for a lot of that not to be read."– Parent[969]*

> *"…the planner has no idea. They haven't read reports. We've just gone through a review last year that outlined for a wheelchair growth, and it was quoted in the report from the physio and everything and we didn't get funded for that. And then we're wasting more time and money, with therapists trying to get more reports and more evidence because they deem that there's not enough evidence in that current report. I might do a carer impact statement all the time. And I feel that that that's not taking into account either they just don't read it, or they skim over it." – Parent[970]*

> *"Dealing with planners and delegates whose knowledge of a disability and their needs comes from a medical model and literature with little or no understanding of real life, comorbidity, and spectrum conditions."- Carer[971]*

This has created a situation where the outcomes of funding decisions are based on the family's ability to advocate and collect evidence rather than the support needs of the child.

This is a particular issue when a child and family is new to the NDIS. At their first planning meeting, families have a significant knowledge and information imbalance, with most new to the world of

disability or developmental delay. They are not familiar with the NDIS or how goal setting or planning works.

The planning process requires knowledge, skills and a good understanding of the inner workings of NDIS. When families are new to the world of disability they are unlikely to have a good understanding of what supports their child many need or how to make a strong case to the Early Childhood Partner or planner. They may not be linked in with providers to provide additional evidence. This results in inequity where funding is based on the family's experience, ability to advocate and resources. For example one parent told us that she speaks to other families with children with the same condition and the funding outcomes can be very variable.[972]

> *"The NDIS model is heavily reliant on caregivers being literate, skilled advocates who are confident interacting with bureaucracy, and understand the child needs well enough to drive access to NDIS funding packages, translate the funds into services and advise on the suitability of services provided. The children and young people Berry Street support do not necessarily have access to such skilled and knowledgeable advocates who have access to internal and external resources to navigate these systems" – Berry Street[973]*

> *"…the professional advocacy organised by empowered parents, in our experience, often results in greater supports in comparison to children who are poor or otherwise disadvantaged, but who may have equal or greater need." – Neurodevelopmental and Behavioural Paediatric Society of Australasia[974]*

> *"Some children have huge plans while other children with higher level needs have smaller plans. There is no clear reason why some clients have bigger plans than others - it is so inconsistent. It also seems to link strongly to education levels of the family - this then makes it less accessible to lower income earning families." – Provider[975]*

We have heard that families feel they have to strongly advocate for their child, often through painting a bleak picture of their child's deficits. This is counter to the strengths based approach SNAICC identifies as a key element of family centred practice for Aboriginal and Torres Strait Islander families (SNAICC is the national non-government peak body in Australia representing the interests of Aboriginal and Torres Strait Islander children and families).[976] Families told us about the deep emotional trauma of being forced to adopt deficit approaches to advocate for funding for their child.

> *"As a parent the process of setting up goals and getting funding is traumatic as you get asked to talk about all the "worst" aspects of your child in order to get funding. There is no debrief or counselling after the session to help with the emotional discussion that takes place." – Carer[977]*

> *"NDIS is a deficits-based model of care. As a parent I have to spend hours / weeks going into great detail about how my children struggle and how we struggle as a*

family. It is soul destroying... Planners ripping me apart for being a bad Mum and slashing our plans without any indication why." – Carer[978]

We have also heard concern about the continued use of functional assessments by the NDIA for planning. This further perpetuates a deficit model where the focus is on what the child can't do, rather than what they can do. Planners use functional assessments particularly Pedi-CAT for children to inform the development of plans. There are a number of problems using functional assessments to determine need. Namely that, functional tools such as the Pedi-CAT have not been developed or validated to be used for determining funding.[979] This means they are not fit for the purpose they are being used for.

"Despite abandoning the proposed 'independent assessment' process, the NDIA continues to use standardised clinical tools in its determination of budgets. For example, children and teenagers typically undergo a Pedi-CAT assessment while adults usually complete the WHODAS 2.0 (World Health Organisation Disability Assessment Schedule). Both are clinical instruments that largely focus on deficits and absences while providing only a rudimentary picture of a person's daily life and life chances." – JFA Purple Orange[980]

"The assessment tools used by the NDIS are inherently deficit focused, where people with ASD and carers are repeatedly required to justify why their support needs should be met by the NDIS." - Royal Australian and New Zealand College of Psychiatrists[981]

Function does not equate to support needs or give appropriate guidance on what early intervention supports may be required. Two children may have the same level of function based on the assessment, but have very different support needs. This could be due to their different conditions, age and stage of development, family circumstances, informal and formal supports, or other factors impacting on the child's impairment such as context or environment.

Pedi-CAT has particular limitations for assessing functional capacity of many children, including those with a developmental delay, autistic children, deaf children, very young children, and children with cerebral palsy.[982] Concerns have also been raised about the accuracy of this assessment for children with significant functional impairment in the area of communication and social functioning.[983] We have also heard that PEDI-CAT is not a culturally appropriate way to assess children.[984] This is a significant problem given the composition of children entering the NDIS.

"The NDIA's ongoing use of the PEDI-CAT assessment tool on autistic NDIS participants is inexcusable." – Autism Asperger's Advocacy Australia (A4)[985]

5.4.2.   Families are not supported to understand their child's plans and how funding can be spent

General issues regarding how plans work and how they are used is described in Section 2.2.1. This section touches on distinct challenges faced by children and families.

We have heard that plans are complex and difficult to understand. We have also heard that plans do not provide enough flexibility to meet need or drive innovative, inclusive approaches. For most children funding is provided for capacity building and can only be used for therapy.

We have also heard that families are not getting enough support or advice on how to implement their plans and connect with best practice services.

Plans are complex and do not provide enough flexibility to allow needs-based spending

We have heard that plans are complex and confusing for families. The language used is bureaucratic with lots of NDIS jargon that is not explained. It is not clear how decisions have been made or how funding has been calculated.

Three-quarters of funding (75 per cent) provided to children younger than 9 is allocated to Capacity Building - Improved Daily Living based on annualised plan budgets as at 30 June 2023.[986] There are significant limitations on the use of this category of support. Supports can't be moved from one support category to another, but can be used flexibly within the category.[987] For children younger than 7, early childhood intervention supports can only be delivered by certain allied health or education professionals, or by a therapy assistant operating under the supervision of those professionals, or to purchase disability related health supports.[988]

While there are some support categories that have potential for more innovation, such as community engagement assistance, training for parents and carers and skills development and training, these are buried in a long and complex price guide. The lack of flexibility and support to understand the possibilities can lead to funding being used for continued therapies and/or being underutilised. It can also stifle potential for more innovative approaches that could deliver good outcomes at a lower cost.

> *"For autistic children who have complex difficulties with social interaction the NDIS only seems to want to offer speech therapy, Occupational Therapy, and psychology... Other things are just rejected... Yet the kind of therapy that really helps children and teenagers as they become social is supported social and community interaction... Speech therapy is useful but also isolates a child in a room with a therapist where what really benefits them is to be supported to learn to interact in the wider world by actually doing so. Yet NDIS can't seem to categorise paying someone to take my daughter to a cafe for example because it doesn't seem medical enough.... So they just go for the triad of speech, OT and Psych..." – Carer* [989]

> *"It seems that other supports are not really valued besides mainstream therapies. I understand it's likely easier to justify the cost of mainstream therapy, however being able to attend a one-on-one supported bushwalk with a sibling, rather than sitting in a clinician's room for one hour each week, is likely more effective in getting my son to follow instructions, explore the world with his peers, experiencing new environments confidently - all part of his "NDIS goals", yet this is not covered by his NDIS plan. It*

seems the setting/environment where the therapy takes place is more important than the outcome." – Carer[990]

"Parents and participants need to be supported to think outside the box not discouraged e.g. if a non-registered gymnasium is happy to provide one-to-one sessions with the intention that eventually the person can join a group – this should be funded. Parents should not have to fight for something that has been shown to be helpful in the past." – Provider[991]

Families do not receive consistent, effective support to spend plans based on need

Most families self-manage their children's plans. This provides increased flexibility, including the capacity to pay above or below the price guide and engage unregistered providers. If they are not well-connected into peer support they are reliant on Early Childhood Partners or Support Coordinators for assistance

> *"No one tells you where you can find therapist." – Carer[992]*

Early Childhood Partners are intended to assist families to understand their NDIS plan and connect with supports and services that would best meet the needs of the child.[993] However, we have heard there is limited consistent support for families on how to use the plan, where to find providers or how to choose a provider that would best suit the needs of their child.

> *"Providers are providing so much support that EC partners in theory should provide - relationships and depth of understanding on family dynamics child's strengths are required to know how to best support someone through the disability journey. This doesn't occur in a 1 off phone call or a face to face meeting." Carer[994]*

Funding and staffing constraints means Early Childhood Partners have been diverted from their intended role to carry out access and planning activities. We have heard about inconsistent service standards across organisations and insufficient time and support being provided to help families navigate a complex service system and connect with services. Few families receive funding for a Support Coordinator to fill this gap.

> *"Families and carers of children experiencing developmental delay or disability are faced with understanding and navigating a complex network of services, diagnostic and application processes, and funding streams before they can even access any early intervention supports. For families and carers of young children it's very hard to be and feel informed, and the partner system is not fulfilling that. There is confusion about the role of the partner in planning and the role of the partner in delivering supports... there is inconsistency between partners of services they offer." – SDN Child's Services[995]*

We've heard that the accuracy of the information and advice provided by both the NDIA and Early Childhood Partners is also variable. Families report hearing different advice both between Early Childhood Partners and the NDIA and within the NDIA itself. The NDIA call centre has been

described as frustrating. Staff will sometimes provide different information and at other times will be reluctant or unable to resolve issues. This leads to further confusion and increases distrust between the NDIA and families.

> *"My clients however have been advised by ill formed LACs and Planners that continence in any shape or form is not funded until the age of five!? If a family seeks me out and has requested a continence assessment with toilet training, then I will be the one to assess their continence needs, no matter what their age… Clinical Continence Nurse Consultant recommendations reflect reasonable and necessary value in any age with special needs under NDIS and misinformation based on age should not be shared with families having difficulty with incontinence." – Continence Specialist Services[996]*

All this means that parents don't have access to information or advice to assist them in accessing best practice supports (independent from providers). In consultations, we heard that families had never heard of the terms key worker or best practice before. There is clearly a significant gap in the support provided to families to help them understand and access best practice approaches to early intervention.

> *"I consider myself a fairly capable person. And yet, just from today's conversation, I'm astounded by the amount of things that I still don't know about the NDIS, like the key worker thing, and the best practice guidelines." – Carer[997]*

5.4.3. Funding should be based on need, with dedicated support for families to implement the budget

We are proposing a package of reforms to the NDIS pathway for children. This should see more time spent getting the budget right and giving families far more support to use the funding to get the best outcomes for their child.

The future approach would mean budgets reflect need and are based on a holistic picture of a child and families' circumstances.

There should be more support for families to help them when they are newest to the world of developmental delay and disability. A Navigator should be available for families, consistent with the approach of ensuring Navigators are available for all people with disability. There should also be a Lead Practitioner with dedicated funding to support the child and family. This means there should be significantly more help for families to coordinate a team around the child and ensure all providers use a best practice approach to delivery of support.

These changes will deliver an improved experience and better outcomes for children and families.

Figure 69: Five main areas of change proposed to budget setting, review and implementation

How budgets are set and reviewed	**1. A consistent and approach to identifying need**	• This should be based on support needs rather than deficits. • This should look at the needs and circumstances of the family as well as the child. • The process needs to recognise that children are likely to require more frequent needs assessments.
	2. Needs assessments are used to set the budget	• Requires reliable, structured and valid assessments to identify support needs and intensity. • The NDIA Needs Assessor will identify support types, frequency, and one-off or time limited supports. The assessor should be a highly skilled and experienced decision maker.
How families are allowed and supported to implement their budgets	**3. Funding for a Lead Practitioner and more flexibility**	• Children and families should receive a funding allocation for a Lead Practitioner. • Families should have more flexibility in spending the remaining budget. • This should allow them to use more innovative approaches that promote inclusion and participation.
	4. More support to use budgets	• Requires the creation of two key functions. • A Navigator to help children and families to make a plan of action to use their funding. • A Lead Practitioner to provide advice and support and coordinate the team around the child.
	5. A more trust-based approach to the NDIA overseeing budget use	• Requires a more trust-based approach to how families can and are supported to use their more flexible budget. It should make it easy for families to comply with rules. • Compliance should be encouraged through guidance and support, with more hands-on involvement only ever used where there are serious risks or issues.

Overview of the new approach

We are proposing that the NDIA set budgets based on the holistic needs of the child and family. In line with the approach set out in Section 2.2.2, this will involve a strengths-based approach to understanding support needs. It represents a significant shift from the current approach where plans are built based on individual supports that a planner can approve or decline based on the evidence provided or the strength of a family's advocacy.

Families will no longer need to paint a picture of their child's worst day in order to get the support they need. Taking a more holistic approach to need means there should be consideration of what is required to sustain family functioning and wellbeing. Families should be encouraged to complete a Carer and Family Impact Statement. There should no longer be pressure on families to advocate for supports or spend money on reports that may or may not be read. This is because the budget will

be based on a more structured and equitable way to gather information about the child and family, their circumstances and their support needs. If additional reports are needed the NDIA should commission and pay for them.

The first step in the information gathering process would be a support needs assessment. This would be completed by a skilled and qualified NDIA Needs Assessor who has disability expertise and experience working with children and families and is a trained allied health practitioner or social worker/youth worker or similar. They are likely to have the most suitable backgrounds to be conducting assessments and making decisions based on need. However, formal qualifications may not be available in all circumstances, given other important requirements such as culturally appropriate backgrounds and lived experience of disability.

They would need to have disability training and experience, as well as extensive training to complete a needs assessment. The Needs Assessor would be responsible for making the budget decision and would ensure it reflects the most effective interventions to meet need. This means the majority of families would meet the decision maker. There may be a small number of very large plans that require a higher level of delegation within the NDIA to approve the plan.

The budget itself would be made up of a combination of flexible and fixed categories. It would consist of a flexible budget, an allocation for a Lead Practitioner as a stated support, and any additional stated supports for assistive technology, equipment or other one-off capital costs (if relevant). All children would receive a flexible budget and an allocation of Lead Practitioner support.

To allow families to choose to use a transdisciplinary approach, funding from the flexible budget can be used by families to purchase greater supports from the Lead Practitioner. A transdisciplinary approach is aligned with the best practice principles. Transdisciplinary emphasises working across disciplinary boundaries to create a more collaborative team and removing the focus on individual roles or disciplines for professionals.

Under a transdisciplinary approach, a Lead Practitioner would play the primary role in coordinating the intervention (using the funding allocated as a stated support) and then delivering most (if not all) of the intervention (using funding from the flexible budget). The Lead Practitioner would deliver supports from within their scope of practice (using the funding allocated as a stated support) and some direct intervention strategies from outside their discipline with supervision and support from other relevant professionals chosen by the family using funding from the flexible budget. The effectiveness of this approach is linked to the ability and willingness of the other professionals to release their disciplinary boundaries and work through the Lead Practitioner. It also requires the family to choose to use the flexible budget in this way.

Figure 70: Illustration of future support budgets compared to the current state
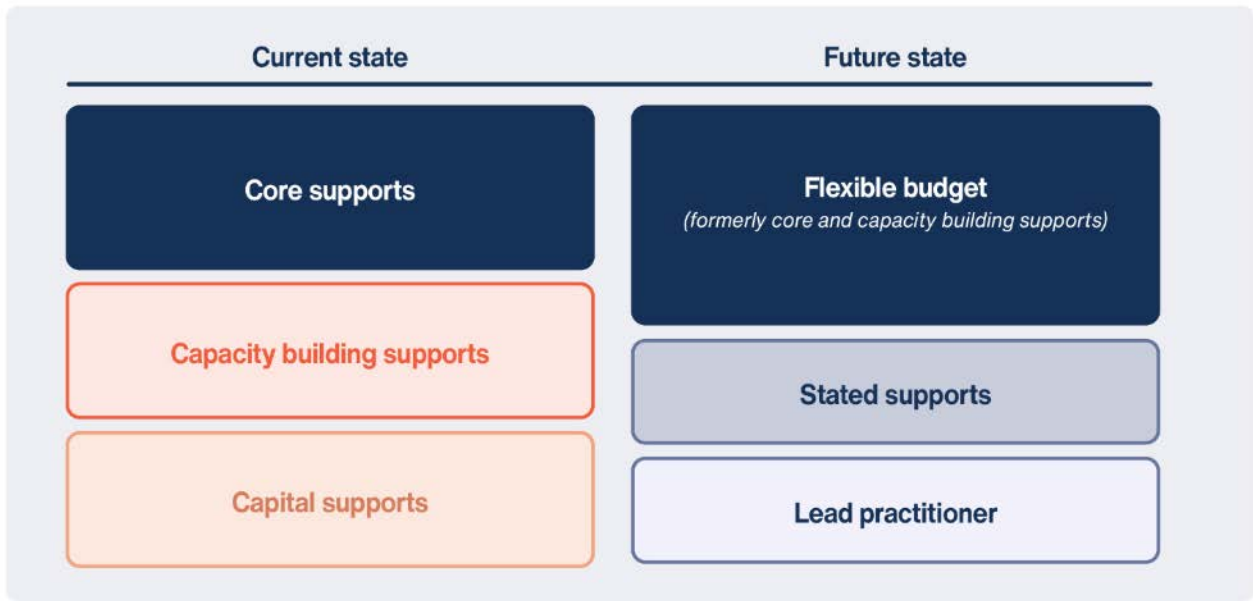
The table below provides more detail on what each of these funding categories is intended to cover and how it will work.

Figure 71: How the different budget categories should work

	Flexible budget	**Lead Practitioner**	**Other stated supports**
What supports are funded:	This funding is based on the needs of the child, including any need to build the capacity of the family. Families may choose to use their flexible budget for additional support from their Lead Practitioner, but not vice-versa. This is to allow families to choose a best practice transdisciplinary approach where the Lead Practitioner plays a primary role in coordinating the intervention and delivering most (if not all) of the intervention. This is possible as the Lead Practitioner should be a qualified allied health practitioner, developmental educator or early childhood educator who is trained in an approach based on best practice principles.	This funding is based on the needs of the child, including any need to build the capacity of the family. This covers the core cost of delivering the key activities of Lead Practitioner, including (1) identifying and addressing needs, (2) service coordination, (3) information and advice, (4) emotional support, and (5) developing self-advocacy skills. Funding will be dedicated to these activities to ensure there is clear accountability for these activities to occur. The amount of funding may be based on levels that reflect different needs and circumstances, and expected time and cost for the Lead Practitioner to perform these activities.	This funding is based on the needs of the child, including any need to help the family support the child. This funding is for any additional non-labour based supports such as assistive technology, equipment or other one-off capital costs. The amount of funding will be based on the expected or actual cost of the item (depending on how bespoke the support is and whether there is a commonly accepted price). It may not be relevant for many children and families depending on their needs.
What did this used to:	This covers supports that were formerly funded as core supports and capacity building supports (but was mostly capacity building supports).	This covers supports that were formerly funded within capacity building supports (but was often not used by families in this way).	This covers supports that were formerly stated supports or non-labour costs across the budget categories.

	Flexible budget	Lead Practitioner	Other stated supports
Who chooses providers:	Families choose from registered providers.	Families choose from registered and approved Lead Practitioner providers.	Families choose from enrolled or registered providers (the specific registration requirements may vary on the specific support).
How are payments made:	Families choose to use funding flexibly and choose providers. Families pay providers through the real time claiming platform.	Families choose a Lead Practitioner who has been approved. Payments will be made by the NDIA on behalf of the family. Families confirm the required services have been performed each month before payment is made.	Families choose providers who meet the required enrolment and/or registration requirements. Payments will be made by the NDIA on behalf of the family. Families confirm the required items have been provided before payment is made.

Children and families would then be supported by their Navigator to decide how best to use their budget and develop an initial plan of action in line with the objects of the NDIS (see further detail below). The Navigator should help the family to select an approved Lead Practitioner who should play a more hands-on role in the coordination and delivery of support for the child and family. The plan of action should then be regularly updated once the Lead Practitioner is on-board. The Navigator will retain responsibility for supporting the family with administrative tasks and provide a level of oversight to ensure the Lead Practitioner is working for the family.

The Lead Practitioner will play a more specialised role coordinating and providing supports for the child and family. They will guide families towards a best practice approach by helping to coordinate a team around the child. The role of the Lead Practitioner is outlined in detail in the best practice section of this chapter (see Section 5.2.7).

Consistent with the approach outlined in the participant's section (see Section 2.2.2), there will be a more trust-based approach to how the NDIA oversees budget use. This is underpinned by the significantly higher level of dedicated support from the Navigator and Lead Practitioner to help the family implement the budget.

Each of these approaches should be implemented gradually using an iterative, inclusive approach to designing and testing and ensure current children and families experience a smooth and fair transition to the new arrangements.

Figure 72: Outline of the new approach of setting a budget for a participant (who has already met access)
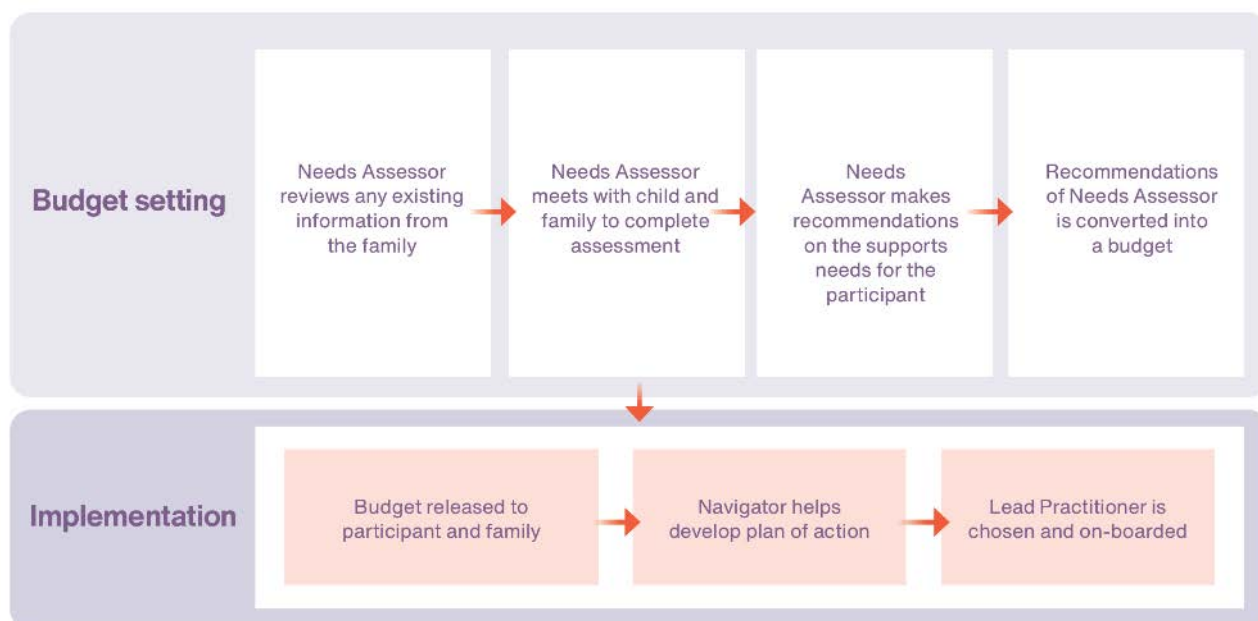
How plans are set and reviewed

In the future, NDIS budgets should be determined at a whole-of-person level. This should be based on a holistic assessment of need, including consideration of what is required to sustain family functioning and wellbeing. This contrasts with the current approach of negotiating over whether each support is reasonable and necessary.

Budgets are set at the whole-of-person level using needs assessments

We are proposing that the concept of reasonable and necessary should apply to the whole budget rather than for each specific support item, in line with the original intent of the scheme. This would be implemented through the introduction of a holistic needs assessment and changes to section 34 of the NDIS Act.

This would involve a more structured way to gather information about children and families, their circumstances and support needs to inform budgets. The new process involves three key components:

> A customised NDIS assessment process for information gathering. This assessment must be designed with the disability community to be both effective and acceptable – principles to guide the design process are included in the participant's section (see Section 2.2.2).
> A skilled NDIA Needs Assessor who is responsible for completing the needs assessment and making a recommendation about a child's support needs and support intensity.
> Method to use the needs assessment to determine a reasonable and necessary budget.

These components are considered in detail in the following sections.

A customised NDIS needs assessment process

Under the new approach, the NDIA will use a comprehensive assessment to consider a child's support needs, including their circumstances (for example, family supports), life stage and environment. Further background on the needs assessment is included in Section 2.2.2.

A new approach is required to assess the support needs for children. Budgets should not be built based on an assessment of functional impairment. This is because two people with the same functional impairment could have different support needs. Budgets should instead be built based on an assessment of support need. This means the NDIA must stop using the functional capacity tools currently being used to inform budget setting. They are not fit for purpose.

A valid and reliable NDIS needs assessment will need to be developed to generate a holistic picture of support needs for children (taking a family-centred approach). There are supports needs assessments for children that have been used domestically and internationally. The existing needs assessment approaches provide a sound starting point to learn from. However, there is no single assessment currently fit for purpose for understanding the support needs, circumstances and life stages of the diversity of children in the NDIS. Importantly, the existing assessments have only been validated for some conditions and none of the assessments included in the case studies are validated for children younger than 5. We have intentionally not attempted to select or recommend any one or more of these particular assessments for children or for adult participants.

There will therefore need to be significant work to design, test and refine an assessment process for children in the NDIS. This presents an opportunity to ensure that the assessments are established through an inclusive and highly transparent process of designing, testing and refining. This is a critical process - without legitimacy the assessments will ultimately fail.

Short case studies have been included for:

- Paediatric Care and Needs Scale (PCANS).
- Supports Intensity Scale Children's version (SIS-C)

Short case studies for assessments used for adults have been included in Section 2.2.2, including the Camberwell Assessment of Need (CAN), Camberwell Assessment of Need for adults with Developmental and Intellectual Disabilities (CANDID), Care and need scale (CANS), Instrument for the Classification and Assessment of Support Needs (I-CAN), and Supports Intensity Scale Adult version (SIS-A).

Figure 73: Examples of case studies for existing needs-based assessments

Paediatric Care and Needs Scale (PCANS)	
Overview and current use • The Paediatric Care and Needs Scale (PCANS) was adapted from the Adult Care and Needs Scale (CANS) assessment tool in 2008 in the UK. • It measures the type, extent and intensity of support needs at any stage in the recovery process for people aged 5 to 15 with an acquired brain injury.	
Domains and scoring	**How the assessment process works**
Domains: The Needs Checklist puts health and social domains of life into groups to assess the level of support required. • **GROUP A**: Requires nursing care and/or support or monitoring of severe behavioural/cognitive disabilities and/or assistance with very basic activities of daily living • **GROUP B:** Requires assistance, supervision, direction and/or cueing for basic activities of daily living • **GROUP C**: Requires assistance, supervision, direction and/or cueing for instrumental ADLs and/or social participation: • **GROUP D**: Requires supports • **GROUP E:** Does not require supports **Scoring:** Depending on yes/no responses to a 'needs checklist' a support level is assigned to each group to determine the overall level of need (the length of time that an individual can be without support).	**Process:** The assessment is conducted by an assessor who has detailed current knowledge of the individual. Nominees or a support person known to the individual or the person with the brain injury directly can also contribute to the assessment. Assessors can also complete an assessment on the basis of information derived from the patient's medical record. The assessment may take up to an hour to complete. **Assessor Skills and Training:** Training is available for the CAN-R, which is the most comprehensive version of the CAN assessment. However, the tool has been designed for use by all health care professionals and does not require additional formal training. **Assessment Model:** The assessment model focuses on a number of factors, including (but not restricted to) • the severity of an individual's limitation • the combined effects of all the limitations • the influence of other impairments such as memory • contextual factors, such as the availability of environmental supports (equipment, aids, services, social supports)
Source: PCANS-2 Manual April 2015.docx (nsw.gov.au)	

Supports Intensity Scale Children's version (SIS-C)

Overview and current use

- It was developed and is administered by the American Association on Intellectual and Developmental Disabilities (AAIDD).
- A detailed needs-based assessment tool designed for children aged 5 to 16 years with intellectual and developmental disabilities.
- The SIS-C was normed on a population of over 4,000 children with intellectual and developmental disabilities.

Domains and scoring	How the assessment process works

Domains:
The SIS-C measures an individual's exceptional medical and behavioural support needs and support needs for life activities in the areas of:
  1. Home living
  2. Community and neighbourhood
  3. School participation
  4. School learning
  5. Health and safety
  6. Social activities
  7. Advocacy
 	
Each area has more detail activities which are scored to determine the level of support needs.
 	
Scoring:
The assessor ranks each activity using a Likert scale according to frequency, amount, and type of support needed. This provides a support intensity score for each area and a total score.
	Process:
	Can take 2-2.5 hours to conduct the interview only. Involves a semi-structured interview and order of completion does not impact the results.
	
	Assessor Skills and Training:
	Assessors should be trained in the SIS-C to administer it. AAIDD recommends that the SIS is administered by a professional who has completed a 4-year degree program and is working in the field of human services. Others who have experience conducting individual assessments and possess an extensive knowledge of behavior rating or psychological testing principles can also administer the assessment.
	
	Assessment Model:
	The SIS suite of tools shift the focus from deficiencies to support needs, by evaluating the practical supports a person needs to lead an independent life. It also captures the needs and goals a person wants to prioritise, as well as medical and behavioural information.

Source: https://aaidd.org/sis/sis-c and https://www.aaidd.org/sis/faqs	

A skilled NDIA Needs Assessor

A key element of the future approach is having a skilled Needs Assessor who is responsible for completing the needs assessment. The Needs Assessor is also the reasonable and necessary decision maker. This is the same as proposed for participants over the age of 9.

The Needs Assessor should meet the general requirements described in Section 2.2.2.

However, there are additional requirements to reflect the time sensitive period of development during the early years.

To accurately assess the needs of children, Needs Assessors should have training and experience in working with children and families. They must be comfortable working in natural environments such as the family home or education settings. They should have the expertise to involve and coordinate the input of others in the assessment process depending on circumstance. For example, this could include input from early childhood educators or child protection case managers.

Assessors must also understand early intervention and have a strong understanding of best practice supports for young children. These assessors must be able to clearly assess both the need for early intervention and other support needs. They will be part of an assessor team and will be able to draw on a breadth of expertise in understanding need.

The accuracy and validity of the needs assessment process are critical to ensuring the budget is appropriately matched to need.

Method to ensure the budget is appropriately matched to need

Once a needs assessment has been completed, there needs to be a methodology to convert the findings into a reasonable and necessary budget. This creates an assessment-informed budget.

There are two different approaches government could choose to guide the future approach for budget setting for all participants. Budgets could be individualised budgets or levels based. An individualised budget results in each participant having a unique and distinct budget. A levels based approach would group participants into distinct levels each with its own pre-defined budget amount. Each person assigned to the same level would receive the same budget. This is the approach to providing Aged Care Home Care packages in Australia. Section 2.2.2 provides further detail on these options and the relative benefits and risks of each approach.

There has been a clear preference from the disability community for individualised budgets to continue. There are strong benefits from continuing with an approach that is similar to how budgets are currently developed. This should be weighed against the more intensive assessment process required to set an individualised budget compared to a levels-based budget. The extra time involved will be seen as a positive by some and may be seen as a burden by others.

There is one key distinction between adults and children when it comes to needs assessments. The early years are a period of rapid growth and development. Needs assessments would therefore need to be undertaken relatively frequently to ensure budgets remained calibrated to support needs. Older participants in contrast may only require a needs assessment every few years. An

older participant may be more comfortable with an intensive assessment on the basis that it only occurs every few years. Children and families however may be may be less comfortable or willing to undergo more regular intensive assessments.

Utilising a levels-based approach reduces the complexity and duration of the needs assessment. The assessment would need to be able to identify broad difference in level of need rather than a specific level of funding. The additional flexibility provided in the budget may mean that less time is needed to identify specific support items, as families can flexibly choose those supports later.

A levels-based approach could therefore be suitable for children under 9 as they are already grouped by their age and need for early intervention supports. It is currently unclear exactly how much the support needs of young children with developmental delay or disability differ across the population. There is currently little difference in the value of most plans for young children, particularly because they are primarily capacity building supports informed by the Practice Guide. This means that children and families are currently going through an intensive planning processes to arrive at a plan value that could have been determined in a much simpler way. It is unclear if this is based on similarities in need of the children, and/or the policy approach taken by planners in making reasonable and necessary decisions. Figure 74 below illustrates the limited variance in the value of plans for the majority of children younger than 7.

The testing of the needs assessment should consider whether a levels-based approach may be more suitable for the early intervention needs of children under the age of 9. It should specifically consider whether there is a relative benefit in using a less intensive assessment process to inform a levels-based budget. Any levels-based budget would however still require exceptions and add-ons available for children with higher or atypical or very complex support needs.

The results of the testing should be brought to Disability Reform Ministers for consideration and approval prior to implementation. The approach will need to have the support of families and the disability community to be successful.

Overview of the current plan distributions

At 30 June 2023, there were 145,000 children younger than 9 with an active plan (Figure 74). When analysing the annual funding for capacity building daily activities it is clear there is little variation for the majority of these children, notably that:

- 27 per cent receive less than $15,000.
- 53 per cent receive $15,000-$21,000.
- 20 per cent receive greater than $21,000. [998]

This shows that over half of children have very little difference in the total amount of capacity building daily activities. Daily activity core funding is only provided for 12 per cent of children and assistive technology for seven per cent of children.

Figure 74: Distribution of plan values by support category (note that the bottom 1% and top 1% have been removed to improve readability of the chart) [999]
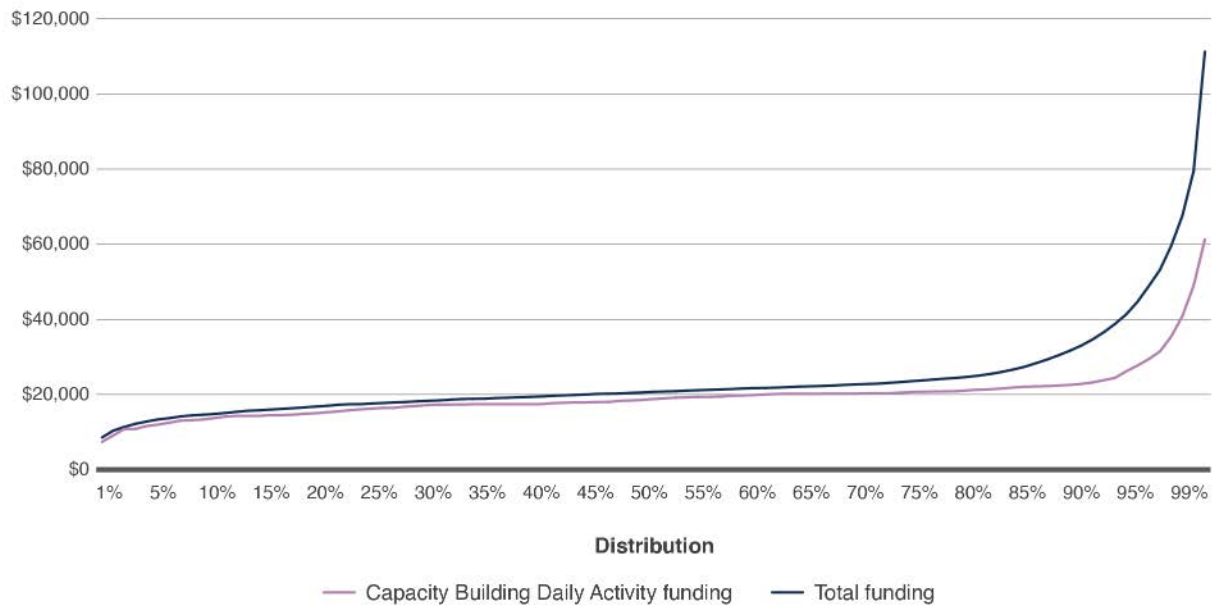
How children and families are supported to use budgets

The needs assessment described above should deliver a more consistent budget that is simpler to understand. Children and families should also have access to significantly more support to use the budget.

A combination of flexible and fixed budgets

We are proposing a simpler approach to budgets for children. The budget itself would be made up of a combination of flexible and fixed categories (as stated supports). It would consistent of a flexible budget, a Lead Practitioner, any additional stated supports for assistive technology, equipment or other one-off capital costs (if relevant). This is illustrated in Figure 70 above.

All children would receive a flexible budget and Lead Practitioner support. Other stated supports would be added case-by-case based on need. The flexible component would be able to be used in a way that meets the needs of the child and family.

Given that the Lead Practitioner would be selected to align with each child's area of greatest support needs we would expect that a standard approach should be taken to the allocation of funding to the Lead Practitioner. How the funding would be allocated should be designed with families, representative organisations and experts.

There should be a focus on understanding when families may choose a transdisciplinary approach that is aligned with the best practice principles. The mechanics of the approach should make this possible.

A transdisciplinary approach would mean that there is a fixed amount of funding to ensure the Lead Practitioner can play a coordinating role as a minimum (as the stated support). There would then need to be consideration of how much funding is included for the Lead Practitioner to deliver supports within their scope of practice (based on need).

This should be considered alongside the flexibility in the remainder of the budget to allow families to choose the Lead Practitioner to deliver some, most or all of the support. The Lead Practitioner can then deliver supports from within their scope of practice (using funding dedicated for the Lead Practitioner) and some direct intervention strategies from outside their discipline with supervision and support from other relevant professionals chosen by the family (using funding from the flexible budget).

Importantly, families should have the flexibility to choose how funding is used for non-stated supports. They may choose a transdisciplinary approach as described above, or an alternative way to meet the needs of their child and family.

Flexible budgets do not mean funding can be used on anything. Families and participants will still be required to use their budgets in a way that's consistent with the objects and rules of the NDIS, including that NDIS funds cannot be used to pay for ordinary living expenses. The Navigator will help make it easy for families to understand what is and isn't allowed. This should be complemented by a compliance model that assumes most families will seek out supports that are likely to work for their child and are doing the right thing.

Where issues emerge with how NDIS funding is being used, compliance should be encouraged through a graduated approach to enforcement (see Section 2.2.2). It will be made clear to families that if they are trying to do the right thing they will not be penalised for an error. This is a critical part of improving trust between the NDIA and participants. The future approach should also be much clearer that there is no relationship between spending in a previous year and future budget decisions. A valid assessment of need should remove any need for the NDIA to use an individual's previous spending as a way of allocating funds for future budget periods.

Greater support for families

A key element of our proposed future approach is much more support for children and families to make a plan of action to use funding and better understand what best practice is. This would be provided by:

- Navigator to support with administrative tasks, including developing and updating the plan of action.
- Lead Practitioner to provide more specialist advice on best practice approaches and helping to coordinate the team around the child (including other providers).

Navigator

All children and families should have access to Navigators to assist them in making a plan of action to use NDIS funding, connect with appropriate services and locate and select providers. Further detail on Navigators is provided in Section 3.1.6.

Navigators should be required to have good local knowledge and an understanding of best practice for children. They should support families with the administrative side of finding services and supports, such as contacting providers, negotiating rates and appointment times.

They should also provide a level of independence from the Lead Practitioner and help to avoid the potential for client-capture. They should also be the point of contact if circumstances change or families need to change Lead Practitioner, including as the child transitions out of the early childhood approach when they reach the age of 9.

The Navigator should help the family to select an approved Lead Practitioner who will play a more hands-on role in the coordination and delivery of support for the child and family. The plan of action would then be regularly updated once the Lead Practitioner is actively supporting the family.

Navigators should ensure that children and families are able to access the support they need and have a consistent contact to help demystify the NDIS.

Lead Practitioner

Children under the age of 9 should receive support from a Lead Practitioner to provide advice to the family and help coordinate a transdisciplinary team around the child.

The Lead Practitioner should be required to have degree level qualifications in allied health or other relevant discipline and have expertise in child development to be able to support families in an evidence informed way. They should support the family to ensure that a best-practice approach is used across all early intervention supports for the child and family.

There will need to be a close working relationship between the Navigator and Lead Practitioner to effectively support the child and family. This requires consent for direct communication between the Navigator and Lead Practitioner to avoid confusion or overlapping roles.

Figure 75 provides an overview of the roles and responsibilities for the Navigator and Lead Practitioner.

Figure 75: Summary of roles and responsibilities to support participants with an NDIS budget.

	Navigator	Lead Practitioner
Basics		
Eligibility	All children and people with disability	Children under 9 and their families
Choice	Able to select approved Navigator	Able to select approved Lead Practitioner
Service requirements	Set by NDIA through contract	Set by NDIA through contract
Regulation	Registered provider	Registered provider
Navigator primary activities		
Support to understand and access the NDIS	Yes	No (is separated from access)
Developing and updating plan of action to use a budget	Yes	No (provides advice to the family)
Identifying or engaging new providers with family	Yes	No (is separated from provider choices)
Primary activities for both		
Find and access mainstream and foundational supports	Yes	Yes
Help to implement budget and coordinate supports	Yes (leading selection of providers and admin)	Yes (leading coordination of chosen providers)
Provide reporting back to government	Yes	Yes
Lead Practitioner primary activities		
Identify and address family needs and priorities	Yes (additional support)	Yes
Deliver early childhood supports based on need	No	Yes (if requested by the family)
Support to develop self-advocacy skills	No	Yes
Provide emotional support to family	No	Yes

Approach to engaging the Lead Practitioner

The Review strongly believes that families require much more support to understand and engage best practice supports for their children. The Lead Practitioner should play a key role in this.

To ensure a high minimum standard, the Lead Practitioners should be commissioned by the NDIA. Specific service delivery requirements for the Lead Practitioner should be set by the NDIA through

contractual arrangements. The NDIA should make payments directly to the Lead Practitioner to enable these contractual arrangements to be in place (following confirmation each month from families that the service has been provided).

The contractual arrangements should include, for example, referral acceptance arrangements and matching of Lead Practitioners to individuals, minimum staff and training requirements, disciplines to be employed, specific service models to be delivered, and approach to monitoring outcomes and Lead Practitioner performance.

This would be addition to requiring that the Lead Practitioner is registered, consistent with the graduated risk-proportionate regulatory model (see Action 17.1) and supported by strengthened Early Childhood Practice Standards.

There should be sufficient market depth to allow families to have a choice of Lead Practitioner and contestability to incentivise higher performance by Lead Practitioners, including allowing new entrants to enter the market where they are able to meet the requirements.

A more trust-based approach to the NDIA overseeing budget use

The NDIA should take a more trust-based approach to the overseeing budget use for families. This is consistent with the broader recommendation for all participants.

Shifting to a trust-based approach of providing families with the support they need to make choices that work for their child and family will be a significant positive change for the NDIS. Having significantly more support available to families from Navigators and Lead Practitioners should mean they have more information and support to make decisions about how their child's funding is used. The NDIA would still need to ensure that funding is being used appropriately. All payments should be visible through the future real time claims management system. This should be complemented by a compliance model that assumes most families will seek out supports that are likely to work for them and are doing the right thing. More detail on this proposal is provided in Section 2.2.2.

5.4.4.   Case studies demonstrate how budgets and plans should work

The two case studies below for Clementine and Malik provide further detail about how the changes described above should work in practice. The case studies highlight differences between how the current planning process works and the future budget setting approach would work and how the Lead Practitioner and Navigator would work together.

Case study 15: Clementine, 23 months old, diagnosis of Williams syndrome

Clementine lives with her Mums Poppy and Lola in the inner west of Sydney. Clementine is a very smiley toddler with bright red hair and sparkling blue eyes. Clementine much prefers talking to sleeping. Both parents work, but Poppy works part-time so she can support Clementine's development and inclusion.

Clementine has had an NDIS plan since she was about one month old.

Clementine has Williams syndrome, and also has a number of health conditions that require regular follow up at the hospital. Poppy uses a Plan Manager and is Clementine's Child Representative.

Current experience

- Poppy has spent the last three months pulling together evidence including reports from Clementine's Physiotherapist and Paediatrician. Her Paediatrician has recommended that Clementine start regular Speech Therapy and Occupational Therapy.
- Poppy isn't sure when she will fit in more therapy visits, as she already takes Clementine to Physiotherapy once per fortnight in North Sydney. Clementine also really enjoys Rhyme Time and Playgroup on Mondays and Wednesdays. A space has also just opened up at the local Council-run childcare centre.
- She has heard from other parents that if she doesn't have enough evidence at the planning meeting then she won't get the support Clementine needs. This makes Poppy worried because she knows early intervention is critical to getting good outcomes for Clementine later in life.
- Other parents have also told her that it's really important to talk about Clementine on her worst day. They have also suggested that she talk about how she and Lola are struggling as a couple so that they can get some core supports.
- Poppy is contacted by a new representative from the Early Childhood Partner, Peter, to arrange the plan review. When Poppy gets off the phone, she complains to Lola that she wishes she could choose a different organisation.
- Poppy sends Peter the evidence and information she has been working on, including documents from Clementine's Physiotherapist and Paediatrician.
- The meeting is at Peter's office and Lola has to take the day off work to mind Clementine so Poppy can focus on the planning meeting.
- Clementine recently started walking on Mother's Day, but Poppy doesn't feel comfortable sharing this in case it impacts her plan budget. Instead, she starts telling Peter all the things Clementine can't do, like put two words together, or complete a simple puzzle. It feels really cruel and Poppy is struggling to hold back tears.
- She can't stop crying when she starts talking about her and Lola as a couple. Peter says that Clementine's grandparents should help out more. Poppy doesn't feel safe to share that she and Lola are estranged from both sets of parents.
- The meeting is over fairly quickly, and Peter doesn't give any kind of indication of what he might recommend.
- Weeks pass, and the end date of Clementine's current plan is imminent. Poppy hasn't heard anything and phones the NDIS call centre who say the plan approval is in progress and they can't give her any kind of timeframe. After sending multiple emails to Peter, Poppy receives a notification that the plan is available on the portal.
- The budget is much less than what was recommended and requested. The plan also goes for two years. Poppy has no idea how the budget was worked out. There is nothing explaining what was discussed in the planning meeting or how the discussion links to the final budget.

- The plan approval letter says its 'parental responsibility' for mothers to care for their children, and that they should use informal support or childcare for respite.
- Poppy shares her experience on a Facebook group. Another Mum shares that she has a child of the same age and her budget was quite a bit more than what Clementine got. Poppy is distraught and feels like she has let Clementine down.
- Peter contacts Poppy for a plan implementation meeting but Poppy doesn't want anything to do with him and still wishes she could choose another organisation. She starts preparations for an appeal of the decision.

Future experience

- Daisy also lives in the inner west of Sydney and has been assigned as Clementine's NDIA Needs Assessor. With Poppy's consent, she receives Clementine's last budget, her most recent functional capacity assessment and other evidence submitted in the previous planning meeting. Poppy also uses the new NDIS Participant Portal to share the vision for Clementine's life that her she Lola developed in a family capacity building session.
- Two years is a long time in the life of a young child, so Daisy reads the quarterly progress reports and most recent case conference notes to understand where Clementine is up to developmentally. She notices that Clementine has recently started walking and is due to start one day a week of childcare in the New Year.
- Daisy prepares detailed notes to pull all of the information together. This starts to give her an idea of where to start the needs assessment with Clementine and where she'll need to ask most of her questions.
- Poppy asks Daisy to meet her, Lola and Clementine in their house. Clementine offers Daisy a seat at her tea party. Clementine happily chats to Daisy and shows her around her room to all her favourite things for about half an hour until she announces she is hungry.
- Lola takes Clementine to the kitchen while Daisy and Poppy speak. Daisy comments on Clementine's vocabulary, and Poppy says their next goal is to get Clementine to combine two words together.
- Daisy and Poppy work through the needs assessment process together, including how Lola and Poppy are functioning and what kind of support they have around them. Daisy notices the mattress on the floor in Clementine's room and asks if Lola and Poppy are getting enough sleep. They are not.
- Daisy contacts Lola and Poppy to share how she has assessed Clementine's need so far across each domain. She checks her notes and assumptions with them.
- Daisy completes the budget calculation based on the needs assessment, this includes funding for a Lead Practitioner.
- Daisy shares the completed needs assessment with Poppy and Lola on the NDIS Participant Portal, along with a budget. The budget contains an overall sum in the flexible budget as well as a clear stated amount for Lead Practitioner support. Although the budget is different to Clementine's previous one, Poppy and Lola can see that Clementine's needs are accurately reflected. They are worried she doesn't have enough support to do all the therapy

recommended by professionals, but agree to be connected with a Navigator to help work through what is possible before they ask for a review.

- Ricky is Clementine's Navigator. He helps Poppy and Lola to understand how a Lead Practitioner works and how they will draw from the input of their transdisciplinary team to support Clementine across all her areas of need. Poppy and Lola are skeptical, but agree to trial the Lead Practitioner to see if it works for their family. Ricky helps Poppy and Lola to make a plan of action based on Clementine's needs assessment. They agree to prioritise supporting Clementine's sleep, speech and transition to childcare over the next 12 months.

- Ricky helps Lola and Poppy to connect to a sleep centre where they cut down Clementine's day sleeps, and manage to get her into bed by 7pm each night.

- Ricky gives Lola and Poppy some ideas for local Speech Therapists and they select Ruby to work as Clementine's Lead Practitioner. Ruby is shortly about to start a group based speech program that teaches parents how to support their child's communication in everyday activities. Lola and Poppy decide to enroll in the program, which runs in the evening so both parents can be involved, Ricky suggests they could use some flexible funding to attend the program. Lola and Poppy agree, and extend the hours they engage a support worker to make it a regular date night at their favourite Vietnamese restaurant over the 10 week program.

- Ruby supports Poppy and Lola with Clementine's transition to childcare. The centre receives a copy of Clementine's vision and notes her strengths and interests. They notice she shares an interest in tea parties with another little boy called Robbie and help support a friendship to develop. Ruby shares with the educators the goals and strategies that Lola and Poppy have been implementing at home to get Clementine to combine two words. The Educators incorporate these into their interactions with Clementine, particularly at meal times and when Clementine is wanting more of an activity.

- Poppy and Lola notice how much Clementine is learning and developing from her peers from her time at child care. Clementine is invited to the park for playdates, where she builds her core and arm strength on the equipment. They realise how many opportunities there are for her to practice skills every day in a fun way, without needing to involve more therapists in their lives.

Case study 16: Malik, 3 years old, male, developmental delay, section 25 (early intervention requirements) plan of action

Malik has just met access under developmental delay criteria. Amira and Kareem are keen to establish a plan to connect to services and supports. They have no experience with disability or developmental delay and are confused about where to start.

Current experience

- Sarah contacts Amira and Kareem to let them know that Malik has met access. She asks when they would like to set up a planning meeting and says her first appointment is in 2.5 weeks.

- Sarah provides them with an option of having it over Microsoft Teams or in the Early Childhood Partner office.
- Amira and Kareem take the first available appointment and request a Microsoft Teams meeting. Ramadan starts in two weeks and they don't want to travel while fasting.
- Sarah emails Amira and Kareem an Early Childhood Booklet, but they don't really understand what kind of goals they should set or what supports are available. They don't fill out all of the booklet.
- Sarah is 15 minutes late to the meeting, and says she has to finish within 45 minutes. Sarah says she has all the information from the Evidence of Developmental Delay form, so she doesn't need to go over that again.
- Sarah asks what goals they have for Malik. Both parents say they just want him to be happy and to be able to communicate his wants and needs. Sarah says she will just rewrite those goals into something SMART and functional, but not to worry about it.
- Sarah asks a series of questions, including what community and mainstream supports they are linked in with. Amira and Kareem don't really understand what Sarah means by this and Sarah doesn't elaborate or suggest any.
- Sarah finishes by asking how they want to manage Malik's plan. Amira and Kareem aren't sure what that actually means. They choose Agency Managed because it seems the easiest.
- Sarah ends the meeting after 40 minutes, and Amira and Kareem are unsure about what comes next.
- After six weeks, Amira and Kareem receive a notification that Malik's plan has been approved. Sarah also emails them to tell them the plan has been approved and sends a link to the provider finder tool.
- Amira and Kareem don't understand what the plan means or how to spend it. After three months, Sarah gets a notification that Amira and Kareem's budget hasn't been utilised and emails them to see if they need support.

Future experience

- The needs assessment completed by Lucy in part one of the example is also used to set Malik's individual budget and this is approved and released to the family as Malik's child representatives.
- Clancy gets back in touch with Kareem and Amira to explain next steps and offer support to develop a plan of action for how to use Malik's budget. He explains that there will also be Lead Practitioner who will be able to give them advice and help to coordinate the team of professionals. They feel relieved that they will have someone who has responsibility for giving them extra support and helping make sense of things.
- Kareem and Amira express a preference to be matched with a Lead Practitioner who has a speech therapy background based on his need for communication support and the positive experience they had with Lucy who was a speech therapist.
- Clancy asks where they would prefer to meet, and Amira and Kareem ask him to come to their house on a day that Malik is at preschool.

- Clancy gives an overview of the purpose of the early childhood approach. Clancy explains that the focus is on building the capacity of important people around Malik like his family and his child care educators. He explains that they will have support to do this through the Lead Practitioner.
- Clancy shares the names and profiles of three speech therapists who have capacity to start working with the family straight away. Kareem and Amira select Jamila who speaks Arabic.
- Kareem and Amira share the goals they have developed through their family capacity building program. One of their key goals is one family outing each weekend where they can spend some more relaxed time together. They are also very keen to support Malik's speech development and work collaboratively with the early childhood educators to embed a consistent approach.
- Amira also mentions that she is wanting to explore further study to become a Teacher's Aide. Malik's childcare has no additional capacity to take him on Tuesdays when Amira's classes are. Clancy lets them know that the budget can be used flexibly to engage a carer for Malik while Amira is studying. Amira was excited and said she would explore the availability of a local woman studying occupational therapy that she heard about in the peer support group.
- With consent, Clancy shares the plan of action agreed with Kareem and Amira with Jamila. They agree that Clancy will check back in after about a month and that Kareem and Amira can contact him if they need any additional support with providers or making use of the budget.
- Jamila sets up an initial block of weekly sessions in the family home to work on communication strategies with Malik, Kareem and Amira. Jamila also seeks the input of one of her colleagues, an occupational therapist, on some strategies to support Malik's emotional regulation when he is unable to communicate his wants and needs.
- Jamila also visits Malik at childcare to share the goals and strategies with the educators.
- After a period, Amira feels comfortable sharing with Jamila that she is feeling isolated and low. Jamila lets Amira know about the free counselling through her local caring organisation and supports her to link in with the service.

5.4.5. Action & Implementation Details

📑 Action 6.4: The National Disability Insurance Agency should change the basis for setting a budget to a whole-of-person level, and introduce a new needs assessment process to more consistently determine the level of need for each child and set budgets on this basis

Reasonable and necessary funding for children should be set based on need, including any need to build the capacity of the family to support the child.

This would require reliable and valid assessment processes that provide a structured approach for a Needs Assessor to identify support needs and intensity (similar to the approach described in Actions 3.3 and 3.4 for all participants). This would require a child-

specific assessment(s) that should include observation of the child in natural settings and family feedback. The assessment should enable the Needs Assessor to distinguish between the type of support, the frequency, and one-off or time limited supports.

Existing support needs assessments should be tested with the children and disability types they have been validated for to inform the design of the new budget setting process. Government may choose to link this assessment to an individual budget (described in Action 3.4) or develop a number of funding levels that children with similar needs may be allocated to (with an exceptional circumstances provision for children with very high needs).

Delivering this would require an investment by government to ensure the assessment is delivered by a highly experienced and qualified Needs Assessor (ideally an allied health professional or social worker/youth worker or similar who is experienced with children) who is able to spend sufficient time to understand child and family needs and circumstance.

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should ensure that the customised needs assessment described in Action 3.4 above has a distinct approach for children under the age of 9. An important consideration for children is the principle of proportionality. The intensity of the needs assessment should be proportional to the needs and expected budget of children, including ways to make the assessment dynamic and responsive to the level of need being identified in real time. It is not appropriate for young children on a relatively small budget to be subject to the same intensity of process as an adult on a very large budget.
- Following the development of the needs assessment process described above, the National Disability Insurance Agency should use the level of need determined by the assessment process as the basis for setting a reasonable and necessary budget. This should involve the NDIS Experience Design Office (see Action 24.3) undertaking detailed analysis to determine the most appropriate approach for linking the assessment outputs to a calibrated budget, including whether it.
  - Is an individualised budget reflecting the cost of supports to meet need.
  - Involves the development of a number of funding levels that children with similar needs may be allocated to.
- The Department of Social Services should develop and bring forward proposed amendments to the NDIS Act and Rules to enable the implementation of the proposed needs assessments, including making a reasonable and necessary determination at a whole-of-person level rather than for individual support items and creating assessment-based budgets (see Actions 3.3 and 3.4).
- The National Disability Insurance Agency should begin implementation of the standardised assessment process following rigorous testing and refinement and once

Disability Reform Ministers have endorsed the assessment, budget setting methodology (see Action 3.4) and proposed implementation approach.

- The National Disability Insurance Agency should:

    - Undertake a review of operating guidelines and internal guidance materials to determine the changes required to implement the proposed needs assessments and change to reasonable and necessary determinations.

    - Establish a Needs Assessor workforce of individuals suitably skilled, experienced and trained to undertake the assessment. The minimum requirements of the Needs Assessor workforce should reflect the distinct approach for children and the different circumstances and requirements of children and families. This must include Needs Assessors able to deliver culturally safe assessments for First Nations and culturally and linguistically diverse children and families.

    - Work with other Australian Government agencies, particularly the Department of Health and Aged Care, to establish a consistent approach to engaging suitability skilled and trained Needs Assessors across the Australian Government care and support sector. This should recognise the distinct skill and training requirements of Needs Assessors to be suitable for the NDIS, while seeking to achieve benefits of scale and preventing competition for skilled Needs Assessors between Australian Government service systems.

5.5. There needs to be much stronger ongoing monitoring and evaluation of early intervention effectiveness

Having an effective approach to understanding progress is an essential component of early intervention supports. Being effective means having multiple ways to informally and formally understand progress and outcomes, celebrate achievements and identify barriers to achieving goals and outcomes for the child and family. It means potential adjustments in approach are being proactively identified. This is a critical element of ensuring early intervention supports are more responsive, impactful and meeting the needs of children and families.

However, we have heard there are insufficient mechanisms in the NDIS to monitor development and progress and outcomes in a safe, non-judgemental way. This means there are few opportunities to identify if adjustments in approach are needed to accelerate developmental progress, respond to change or to celebrate progress and achievements.

Understanding how supports are working for children and families must be prioritised. This should be achieved by regular informal check-ins with the family as part of the proposed Lead Practitioner and Navigator roles, semi-regular formal case-conferencing planned and facilitated by the Lead Practitioner, and as-needed updated to the plan of action with the child's Navigator.

These reforms will ensure children are receiving the most effective early intervention supports.

5.5.1. The current pathway is not effective in monitoring progress or evaluating outcomes for children or families

There are few mechanisms in the current pathway to check how supports are working for children and families or to consider whether they are meeting their needs. Families have been left to take on the responsibility of monitoring and adjusting when needed with little or no information, guidance or support.

Currently, the primary mechanisms to review progress are plan check-ins and reassessments conducted by either an Early Childhood Partner or NDIA planner. The connection between these mechanisms and planning outcomes, especially future budgets, means this is not an effective approach to understanding progress.

There is currently very limited involvement of other key stakeholders such as providers or early childhood educators in these check-ins. Mechanisms to support greater use of case conferencing have not been established in the NDIS. This is an important gap in the early intervention approach for children.

5.5.2. Planning is intertwined with check-in's and monitoring

Plan check-ins and reassessments are not effective ways to understand how children and their families are progressing. The general differences between a check-in and a plan reassessment are:

- Check-ins are contacts that happen after plan implementation. They should occur at regular intervals to see how things are progressing. They are intended to enable the planner to understand if supports are meeting the needs of the child and family and if any help or changes are required. They might also happen when plans are either under or over utilised.
- Plan reassessments are intended to be an opportunity to check in about what worked in plans, set new goals and respond to any changes that are required. They happen at longer intervals linked to the planning cycle.

We have heard Early Childhood Partners have not had capacity to deliver their intended role in performing check-ins or actively monitoring progress. We have heard and seen that even when check-ins occur they can be limited to generic emails sent to the family. They may also come from someone who the family are not familiar with.

> *"Monitoring is probably the last thing on my priority list. Unfortunately, I'll get back to anybody who contacts me, but there's definitely lots of families who suddenly pop up on my radar for some reason where I go, 'Oh no, what's happened?'" – Anonymous[1000]*

Part of the challenge for Early Childhood Partners is that performance measures and funding arrangements for their role have been focussed on access and planning activities. There is also no additional time allocated in their funding arrangements to support families with more diverse needs and circumstances. This incentivises more light-touch approaches to check-ins and means that reassessments have not been consistently performed due to workload challenges. Early

Childhood Partners told us that when they do occur, they are not able to act on what is revealed through check-ins for those with higher needs or who might need more assistance.

> *"I wish there was more space to take more consideration for the complex families... you have to do the monitoring for everyone, but what we should be doing is identifying those families that actually need more of your time and more of your support and leaving the families that are quite capable and going along well... I should be spending that energy on the families who really need the support." – Anonymous[1001]*

> *"And I think one of the huge ways that we do monitor risk and harm is through the monitoring throughout the plan. And I would say that that is a challenge because again, the time that's allocated to actually allow for active monitoring is probably not as much as is needed sometimes." – Anonymous[1002]*

> *"We're attempting now to do a proper review check-in and to then book a review meeting. Obviously that's been really inconsistent and has been a pretty sore point, stressful point for the team" – Anonymous[1003]*

We have also heard that planners are not well placed to follow up with families or identify whether supports are achieving the intended outcomes. They are removed from the teams working with children and families and are viewed with suspicion by families due to concerns about funding being cut.[1004]

The connection between a planner and funding decisions means that families are unwilling to share information or reveal any positive progress. Families are unwilling to talk about progress in case funding is taken away.

The link between planning and funding detracts from conversations about developmental progress, achieving milestones and measures of success. This is not the right environment to be doing non-threatening and strength-based check-ins with families.

> *"It's the way the NDIS presents this dollar amount on this plan, and it's just become so much the focus..." – Anonymous[1005]*

5.5.3. There can be limited collaboration or coordination of multiple teams working with children and families

There are a number of key stakeholders involved in the lives of children and families. This can include allied health professionals, developmental educators, early childhood educators and teachers. They often work independently of each other and aren't able to easily collaborate or coordinate supports.

If families chose individual therapy delivered in clinical settings, it is more difficult for individual therapists to work in a coordinated way. This makes checking in on progress more difficult. It also

makes it difficult for families to assess what changes might be needed as they are not closely connected to the supports.

We've have heard that families feel it is their responsibility to link their supports together and encourage collaboration.[1006] Too often, providers are not working to the same outcomes for the child. This is a significant workload to take on. Families do not currently have any support for this additional workload unless they have chosen to engage a key worker using plan funding. However, there is low awareness of the benefits and limited availability of the key worker model. Uptake is therefore very low.

The NDIA has attempted to address this gap. In 2020, the 'Early childhood - Provider report form' was developed as a mechanism for providers to report on achievement of goals for the child and the family.[1007] It is intended to measure the progress and impact of interventions annually, and to inform planning and monitoring of outcomes. Once completed, this form is recorded on the child's NDIA file and is available for planning purposes.

There are significant limitations to this approach:

- It is focused on individual therapy goals, rather than the holistic goals of the family and child.
- It asks the provider to make recommendations about funded supports the child might need. This creates a perverse incentive for the provider to provide a report that suggests more intervention is required.
- It is not mandatory for providers, and it is unclear how much it is actually being used. Due to CRM limitations, there isn't any clear way to identify the number of children who have data recorded on their file from this form.

Most importantly, the form takes a one-way approach to monitoring outcomes. The information is shared by providers back to the NDIA. There is not any mechanism for information to be shared between providers, or for providers to come together as the team of professionals working with the child and family.

A form-based approach is also unlikely to act as catalyst for bringing multiple professionals and organisations together. Information is difficult to share in this way due to privacy requirements and providers are likely to use their own reporting tools which may be similar but distinct from a centralised form. It is also unlikely to interface well with provider information management systems and allow for auto-population of information. This means uptake is always going to be low.

5.5.4. There should be stronger monitoring of progress and evaluating outcomes

The future NDIS must include a more effective approach to monitoring and evaluating outcomes from early intervention supports. This is critical to improve long term outcomes for children.

There needs to be non-threatening and regular check-ins about how the child and family are progressing. Families should not feel like they will lose funding when they have made progress or the expected benefits from early intervention have yet to be achieved.

A new approach to monitoring and evaluating outcomes should make early intervention supports more responsive, impactful and linked to progress. This would ensure children and families have their needs better met.

Separation monitoring and evaluation from budget setting

The future approach to monitoring and evaluation must be separated from the needs assessment and budget setting process. This is critical to ensure that families feel that it is safe to share their progress and is not a way for budgets to be reduced after a positive impact or achievement.

Families are a crucial part of the monitoring and evaluation process because they know their child best. It is imperative that they have trust in the process to share their experience. They would also benefit from more coordinated support from professionals.

The Navigator and Lead Practitioner will both play key roles in monitoring and evaluating outcomes for children:

- The Navigator will play the primary role of ensuring monitoring and evaluation is occurring across the NDIS. They should also perform check-ins with the family and be a part of case conferencing (alongside the role of the Lead Practitioner). They will be responsible for enabling outcomes measurement for all participants, including children. They will also ensure the plan of action has been updated to reflect any changes as a result of the monitoring or evaluation processes.
- The Lead Practitioner will provide specific child development expertise and coordination support. They are responsible for conducting check-in's with the family and coordinating input and engaging with other professionals supporting the child through case conferencing. Coordination of providers will also enable the Lead Practitioner to know how other supports are progressing. They will provide advice to the family where they believe a change is needed. The family however will always remain the decision maker.

Importantly, both the Navigator and Lead Practitioner will be separated from the budget setting process. Information from the monitoring and evaluation may be provided to the Needs Assessor by the family for future needs assessments (where they choose and provide consent). There must be no direct sharing of information from a Navigator, Lead Practitioner or other provider to a Needs Assessor without the express consent of the family.

Using multiple methods to monitor and evaluate progress

The future approach should involve multiple methods to monitor progress and evaluate outcomes from early intervention supports for children. This includes regular informal check-ins with the family, semi-regular formal case conferencing, and updates to the plan of action as needed.

The specific approach should be designed with families, other experts in child development, service models, and outcomes measurement, and representative organisations. This is necessary to ensure the approach is family-centred and supports best practice.

Regular informal check-ins with the family

The Lead Practitioner should regularly engage with the family to understand their wellbeing and how they are progressing. Part of this engagement should involve informal check-ins, which may include understanding:

- How the child is participating and being included in daily activities in the home, community and education settings.

  - Any new approaches or support that the child may need.

- How the family is going, checking in on their wellbeing, resilience and agency.

  - Any new approaches or support that the family may need.

- How the family members are supporting their child's development.
- Whether there are any emerging issues.[1008]

These can occur in the family home or other natural setting chosen by the family to avoid disruptions to the family's routines.

Navigators will also be undertaking and involved in check-ins to understand how the funding is being used and to identify any additional support or change in approach that is required.

Semi-regular formal case conferencing

The Lead Practitioner should plan and facilitate semi-regular case conferencing with the team around the child. The Lead Practitioner should play a key role in coordinating and bringing together providers, the Navigator and other stakeholders for case conferencing.

Case conferencing should involve genuine collaboration and conversations on the effectiveness of support for the child and family. The purpose is to better understand progress, evaluate how the child and family are going and the impact of particular approaches, with a view to identifying any adjustments in approach that may be needed.

Families should be actively involved in these discussions to feel empowered and help them understand their child's progress and how they can best support them. They also need to understand why any adjustment in approach is needed so they can make informed decisions. They remain the decision maker and take advice from the case conferencing process.

The frequency should reflect the needs and circumstance of the child and family, but generally should occur quarterly, depending on progress. They should build on the frequency of the informal check-ins with the family.

> **Box 35: Overview of a case conferencing approach**
>
> Aims:
>
> - Review progress against the plan of action and goals.
> - Review outcomes for the child and family.
> - Celebrate achievements.

- Discuss any barriers to achievement of goals.

How:

- The family sets the agenda for the case conference together with the Lead Practitioner and Navigator so it is family-centred and non-threatening.
- Key stakeholders meet virtually or face to face at the frequency agreed with the family (generally should occur quarterly).
- Key stakeholders includes: child (when age appropriate), family, Lead Practitioner, Navigator, other support providers, and may also include others involved in the child and family's life (e.g. early childhood educator or school teacher).
- Session follows the agenda agreed by the family. They should be action oriented and have clear key steps agreed during and/or soon after the session.

As needed updates to the plan of action

Once a child has a budget approved, the Navigator should assist the family to develop a plan of action to utilise the funding. Initially, this should be primarily based on the needs assessment and any other information the family has about the needs of the child.

The plan of action will set out how the family would like to use their child's budget to meet their needs and goals. The plan of action should be an iterative document that can be updated as needs or preferences change. This is particularly the case for children who are going through significant change as they develop.

The regular informal check-ins with the family and semi-regular formal case conferencing (described above) may result in the family choosing to adjust the approach for how the budget will be used. The adjustments to the plan of action should occur through regular check-ins with the Navigator. Check-ins that discuss the plan of action may involve the family and Navigator only, or the family, Navigator and Lead Practitioner. The specific approach should be chosen by the family depending on their preferences. Some families may not be comfortable sharing the financial information within the plan of action with the Lead Practitioner until they have established greater trust.

Importantly, families should have significantly more flexibility in how budgets will be used in the future. This means that they can be responsive to the needs of the child and family. This may mean that the family needs to spend funding on a support that hadn't been contemplated when the plan of action was established or updated. Families should have the flexibility to do this. However, the plan of action should be updated regularly so that it remains a contemporary document and the Navigator has visibility of any risks of overspend.

The Navigator should have access to the NDIA's PANDA Live system (or equivalent if this system is replaced) which provides real time reporting view of spending and identifies risk factors and provides alerts. This should be more effective in the future with payments being made through the real time claims management system.

Plans of action should not be a set and forget process. They should be a working document for the family and the Navigator to regularly update on a plan, do, and evaluate cycle. This can help ensure that the transdisciplinary team around the child is working to the one plan and one set of outcomes and goals for the child and family.

5.5.5. The future approach to monitoring and evaluation should be designed carefully with families

The future approach needs to be designed carefully with families to ensure the process is family- and child-centred and supports best practice. It should be informed by other experts in child development, outcomes measurement and representative organisations.

There are key dependencies in this approach with the design of both the Navigator (see Action 4.1) and Lead Practitioner (see Action 6.5) functions. Similarly, the design of those functions needs to consider the need to monitor and evaluate outcomes from early intervention supports, particularly for children.

Box 36: Monitoring and evaluation approach design considerations

The future approach should be designed with families and other experts. It should consider:

- How to build transparency and trust into the processes. There is a need to balance rigor with the need to not be invasive or overly burdensome for families.

- How to consistently measure and support the holistic and diverse needs of families, including across different life stages and circumstances.

- How it can be inclusive and appropriate for families with diverse needs and circumstances. The approach must be designed with and to work for more complex families first. In addition, the NDIA must work in partnership with culturally and linguistically diverse and First Nations communities to ensure the monitoring and evaluation approach will meet the needs of their communities.

- The most effective approach to ensure shared and collaborative monitoring and evaluation of progress across multiple professionals, organisations and funding models.

- The supporting materials, resources and measurement tools required. For example, using a tailored approach to assessing functional improvements.[1009] This could draw on existing tools to assess developmental and functional improvements for children, and for family achievements against goals (such as, Child Outcomes Summary Process, Family Outcomes Survey - Revised Version and Goal Attainment Scaling (GAS)-Light). [1010]

◪ Action 6.6: The National Disability Insurance Agency should develop and implement an approach for ongoing monitoring and evaluation of the effectiveness of early intervention for children.

This should involve the Lead Practitioner working with the family and the Navigator to develop a plan of action to guide the family and the team around the child. The plan of action should be regularly and informally reviewed. This should be reinforced by more formal periodic case conferencing with the team around the child to check in on progress and effectiveness of the interventions, and identify any adjustments that need to be made. Families should be actively involved in these discussions to feel empowered and help them understand their child's progress and how they can best support them.

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should design and implement an approach for ongoing monitoring and evaluation of children's progress and the effectiveness of early intervention. It should include:

  - An approach to more regular check-in's by the Navigator and the Lead Practitioner.

  - The team around the child periodically meeting through a mechanism such as case conferencing to evaluate, discuss and report on the child's progress following a period of early intervention. This is expected to include, the family, Lead Practitioner and Navigator. It could also include NDIS providers, mainstream or foundational support providers or stakeholders (for example, early childhood education and care educator or school teacher) and any treating health professionals.

  - An approach to create a safe, non-threatening environment that discusses child and family achievements, what is working well and what might need to be adjusted.

  - Tools for the Navigator and Lead Practitioner to support the family through difficult decision making, including switching providers and/or changing or ending particular support models.

- The National Disability Insurance Agency should begin implementation of the monitoring and evaluation once the reforms to the pathway and Lead Practitioner role are in place.

6. Recovery-focused psychosocial supports in the NDIS and the broader mental health system

- Supporting people with the most significant psychosocial disabilities is and should remain core business for the NDIS. The NDIS has delivered a significant increase in funding for disability supports for people with severe mental ill-health and made a positive difference for many people.

- While the NDIS has improved the lives of many, participants with psychosocial disability continue to experience lower community participation, employment and carer employment than other participants in the scheme.

- Current approaches to eligibility assessment, plan budgeting, planning and plan reviews are not trauma informed. The market has not been sufficiently stewarded to support independence, personal recovery and connection to family and friends for people with psychosocial disability. The scheme is not meeting the needs for people who would benefit from an early intervention approach or participant with highly complex needs.

- The NDIS also does not operate effectively with the broader mental health system and there are inequities in access to mental health services and psychosocial supports outside the NDIS.

- A new NDIS psychosocial disability approach is needed to focus on personal recovery and better connect the scheme with the wider ecosystem (Figure 76). Participants should have access to specialist psychosocial recovery navigation services with expertise in psychosocial supports and trained in trauma-informed support. There should also be an early intervention pathway for psychosocial disability. Participants should receive more guidance from a Psychosocial Recovery Navigator to access the supports that meet their needs and preferences.

- These reforms should be accompanied by increasing the supply of providers with psychosocial expertise, and a more connected, collaborative approach to psychosocial disability across the NDIS and mental health system.

Figure 76: Overview of the continuum of mental health and psychosocial support

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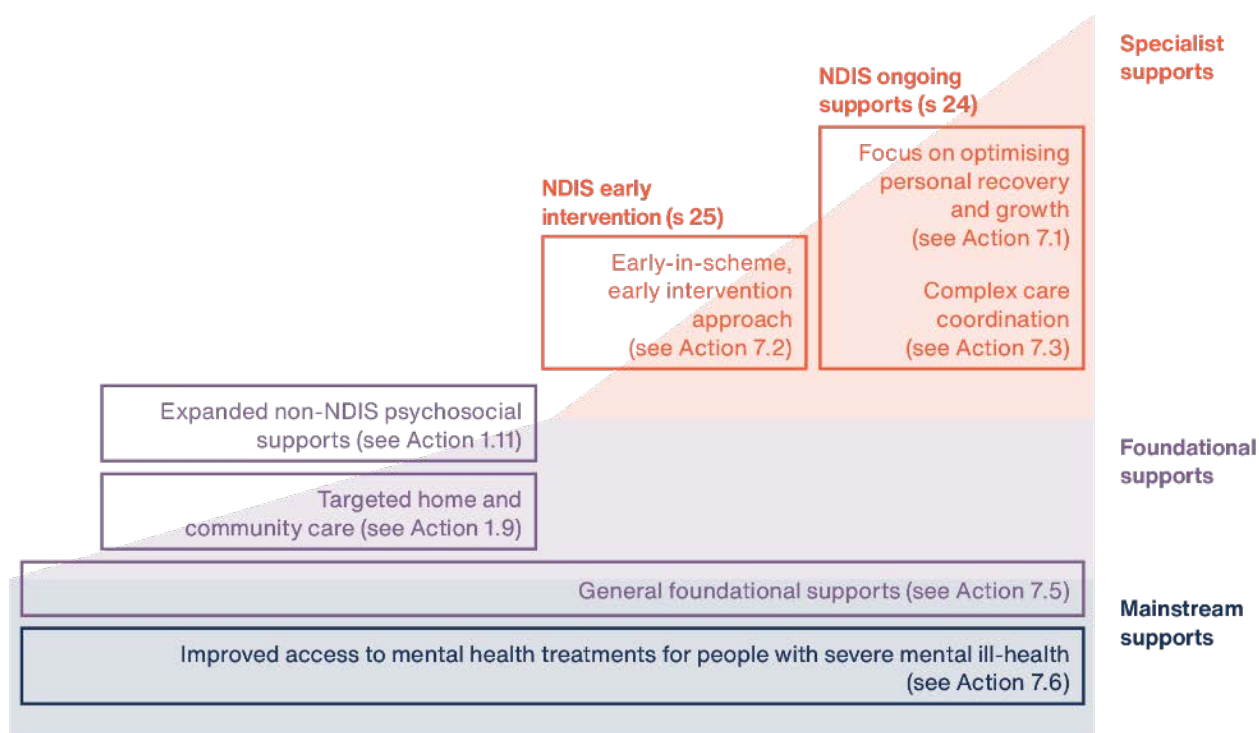
Case Study 17: What the new NDIS approach could look like in practice for people with psychosocial disability

- Brett has a borderline personality disorder which significantly impacts his daily life and resulted in a breakdown in his relationships with his family and friends and his fellow workers. He has a significant psychosocial disability and the mental health treatments he has received have made no difference. Brett enters the NDIS through the early intervention pathway. This is because of his psychosocial disability is likely to be permanent and also has a significant impact on his daily life.

- He is connected to Mary, through the local navigator hub and she introduces him to a service provider that has experience in supporting people with psychosocial disability. With Mary's support, Brett chooses the web-based resources, joins a peer support group and the social skills program offered by the service. He also decides to ask his family and some work colleagues to attend the educational programs run for family and friends. Mary helps Brett connect with a new mental health service who bulk-bills and he continues treatment.

- After two years, Brett considers that his daily living and social interaction skills have improved but comes to recognise that he will have significant disability support needs throughout his life. He asks Mary to assist him with transferring to lifetime supports through a section 24 application. Mary assists him with his access application and he transfers to lifetime psychosocial supports through the NDIS under section 24. This is administratively easier because he is known to the NDIA.

- Brett felt that the early intervention service helped him be as independent as he could be, supported him to seek more mental health treatments and come to terms with having a

lifelong disability. The early intervention service helped him to understand what the NDIS could offer and how to change his supports to his changing needs and improve his confidence and skills in managing his psychosocial disability and his mental wellbeing. He gets on better with his family, friends and work colleagues.

Recommendation 7: Introduce a new approach to NDIS supports for psychosocial disability, focused on personal recovery, and develop mental health reforms to better support people with severe mental illness

📑 Legislative change required

- 📑 Action 7.1: The <u>National Disability Insurance Agency</u> should introduce a new approach to psychosocial disability in the NDIS based on personal recovery and optimising independence.
- 📑 Action 7.2: The <u>National Disability Insurance Agency</u> should establish an early intervention pathway for the majority of new participants with psychosocial disability under section 25 of the *National Disability Insurance Scheme Act 2013*.
- Action 7.3: The <u>National Disability Insurance Agency</u> should establish an integrated complex care coordination approach with public mental health systems for participants with complex needs.
- Action 7.4: The new <u>National Disability Supports Quality and Safeguards Commission</u> should require providers delivering psychosocial supports to be registered, including demonstrating compliance with a new support-specific Practice Standard.
- Action 7.5: <u>All Australian governments</u> should prioritise supports for people with psychosocial disability as part of general foundational supports.
- Action 7.6: <u>All Australian governments</u> should improve access to mental health services for people with severe mental illness and strengthen the interface between mental health systems and NDIS.

6.1. The NDIS has not structured its processes to support participant independence and personal recovery

During the Review, we heard from many people with psychosocial disability, family and carers, providers, advocates, health professionals and researchers – including through submissions, workshops, meetings and engagement led by the National Mental Health Consumer and Carer Forum. We also considered the Productivity Commission's Mental Health Inquiry (2020)[1011] and the report of the Victorian Mental Health Royal Commission (2021).[1012]

Based on what we heard, we identified a range of areas where the NDIS could be improved to support better outcomes for participants with psychosocial disability. Many of the challenges experienced by participants with psychosocial disability are experienced by all participants in the scheme – and would be addressed by the reforms we recommend elsewhere. This section proposes

additional actions to address specific problems and improve NDIS supports for participants with psychosocial disability.

6.1.1. The NDIS does not always work well for participants with psychosocial disability

Support for psychosocial disability is core to the NDIS and its commitment to support people based on functional impairment and not medical diagnosis. The NDIS has delivered a significant increase in funding for disability supports for people with severe mental ill-health. NDIS expenditure for primary psychosocial disability supports was $4.3 billion in 2022-23.[1013] There are 62,000 participants with 'primary' psychosocial disability (10 per cent of all participants)[1014] and an additional 37,000 with 'secondary' psychosocial disability (6 per cent of participants) in the scheme as of June 2023.[1015] (Noting we recommend the NDIS shift to classifying data using the International Classification of Functioning, Disability and Health (ICF), rather than primary or secondary disability – see Action 23.4).

This group of participants have widely varying disability support needs. The severity and permanence of their disabilities is directly affected by participants' abilities to manage and accommodate their mental health challenges, the social determinants of psychosocial disability, level of access to mental health treatments, and the stigma and discrimination that many experience.

The NDIS has made a positive difference for many people.

> *"When the system works well, and the funding we need is given to meet the needs - life is so different for the better. Aside from the challenges I have had with the NDIS … it has also been a blessing for myself and my loved one." – Carer and participant[1016]*

> *"My son spent 28 years constantly in and out of psychiatric hospitals. … Now, 5 years under the NDIS – this is no exaggeration – he's never been to hospital. Now that is an incredibly successful story that the NDIA should be talking about!" – Carer[1017]*

> *"The importance of choice and control, a recovery orientation, life-long support and the successes that can be achieved through a well-functioning NDIS cannot be under-estimated for people with psychosocial disability." – National Mental Health Consumer and Carer Forum[1018]*

While the NDIS has improved the lives of many, we have also heard many negative experiences and outcomes. Participants with psychosocial disability continue to experience lower community participation, employment and carer employment outcomes than other participants.[1019]

> *"My son is safe but he has made no progress … with the NDIS due to lack of knowledge around schizophrenia and comorbid disabilities. He has been enabled, isolated and in one house abused. He needs the security of ongoing support by services who have qualifications. I need to know that when my husband and I are no*

longer around that he will continue to be safe and be able to live his best life." –
Carer[1020]

"No one was interested in my plan or my self advocacy or my decisions about what
would be best for me. I was just an ATM card and it has ruined my trust in NDIA NDIS,
local area coordinators, safeguards … If I knew how poorly I would be treated, I would
not have applied. … I ended up in hospital from the way I was treated." –
Participant[1021]

We have been told that approaches to eligibility assessment, plan budgeting, planning and plan
reviews are traumatising. We were also consistently told that the NDIA and partners do not have a
good understanding of psychosocial disability.[1022] As one participant described, "mental health still
feels like an afterthought of the NDIS."[1023]

"My whole experience with NDIS from start to finish has been stressful and as a client
with psychosocial disabilities it is causing more harm than doing me good … NDIS for
me has hindered me rather than helped." – Participant and carer[1024]

"There is a pervasive theme of distrust and fear that shape how participants
experience and relate to the NDIS." – Advocate[1025]

"Attempting to access NDIS supports and services often retraumatises those with
psychosocial disability due to a lack of psychosocial-specific training for frontline staff
and assessors, and without having lived experience embedded in the agency to help
people navigate the system." – National Mental Health Consumer and Carer
Forum[1026]

Many issues experienced by participants with psychosocial disability are common to other
participants in the scheme – confusing information and processes, little help to navigate the
bureaucracy, and difficulty finding suitable services and supports. These issues are addressed in
other sections of this report (see Sections 2.1.1, 3.1, 4.1.1). A challenge uniquely affecting
participants with psychosocial disability is that NDIS systems and processes do not sufficiently
incorporate a recovery-focused approach.

The NDIS lacks a recovery-oriented approach

Many submissions to the Review pointed to the importance of a recovery-oriented approach. We
accept the World Health Organisation (WHO) definition of recovery:

"For many people recovery is about regaining control of their identity and life, having
hope for their life, and living a life that has meaning for them whether that be through
work, relationships, spirituality, community engagement of some or all of these." –
World Health Organisation[1027]

In 2021, Disability Ministers adopted personal recovery, as defined by the WHO, as a core element
of the future approach to psychosocial disability supports, through the NDIS Psychosocial Disability

Recovery-Oriented Framework. This Framework, developed in consultation with participants, carers and service providers, recognises that recovery is a unique, personal experience, owned and led by the individual. The journey of recovery is one where people discover and pursue their goals and aspirations that go beyond health outcomes and may lead to new purpose and meaning in life.[1028]

The Framework sets out six principles to better support recovery, including valuing lived experience, better operational working arrangements with mental health services, supporting informed decision making, responsiveness to the episodic and fluctuating nature of psychosocial disability, and strengthening the recovery-oriented and trauma-informed workforce.[1029] The NDIS has improved its focus on personal recovery, such as through the introduction of the Recovery Coach support item.[1030]

However, the Framework principles have not yet led to practice change, improved psychosocial competencies for NDIA staff or improved experience of the access, assessment and planning processes for participants. The Framework should be fully implemented along with our recommended actions.

Insufficient funding for effective evidence-based supports

The NDIS provides significant supports for many participants with psychosocial disability: the average annualised plan budget for primary psychosocial disability is $95,100 and, due to plan underutilisation, average expenditure is $71,600 (as at 30 June 2023).[1031] However, we heard from many people with psychosocial disability, family and carers, providers, advocates and researchers that the NDIS is not investing in the right supports to get the best outcomes for participants with psychosocial disability.[1032]

The types of supports the NDIS is funding are strongly weighted towards 'core' daily living and social and community access supports (81 per cent of payments in 2022-23), with a low level of investment in capacity building and very low investment in assistive technology.[1033] There is minimal investment in evidence-based supports for psychosocial disability, including supported employment, supported education, family psychosocial education, digital psychosocial supports and apps, recovery colleges and social skills and social cognition training.[1034]

Current NDIS funding priorities are inconsistent with evidence about the most effective supports. Daily living supports remain essential during an acute mental health episode or on an ongoing basis. However, research and practice in other mental health programs demonstrates that the majority of people with severe mental illness can rebuild and retain daily living skills and community participation, to varying degrees, with the assistance of evidence-based supports.[1035]

Current over-weighting of core supports is influenced by lack of psychosocial expertise within the NDIA, lack of a specialised NDIA service approach for psychosocial supports, and inadequate stewardship of the provider market.

Unclear eligibility for people with psychosocial disability

The NDIS is intended to support people with the most severe psychosocial disability, but the level of severity for NDIS eligibility and the boundaries between non-NDIS supports and NDIS supports

are unclear. The NDIS has not defined the severity range for eligibility. There is limited guidance for health professionals and the NDIA to help guide respective professional and administrative judgements on severity and permanency. This creates frustration and confusion for applicants and health practitioners. It leads to inconsistent NDIS access decision outcomes.[1036]

The consistency of judgements on psychosocial eligibility is complicated by the lack of Australian guidelines on severity and permanency of psychosocial disability. There are no consensus guidelines to guide health professionals' judgements about severity and permanency, and that consider the episodic and fluctuating nature of psychosocial disability. Health professional training programs rarely cover this issue.

Lack of clarity regarding eligibility requirements risks entrenching inequity and placing further financial pressure on the scheme. Unclear eligibility requirements create a risk of higher demand and funding beyond current projections, as the NDIS increasingly delivers supports to a wider proportion of people with mental illness. The lack of an overarching approach to severe mental ill-health across health and disability systems leads to poor outcomes for participants, leaves non-participants without supports, and increases financial pressure on the NDIS.

6.1.2. The NDIS should improve supports for people with psychosocial disability across all aspects of the scheme

To ensure better outcomes for participants with psychosocial disability, reform is required across a number of aspects of the NDIS – eligibility, budget setting, planning/navigation and service provision. There are some specific reforms that can uplift the quality of supports for people with psychosocial disability. These reforms would introduce a more recovery-oriented approach, focused on better supporting people to manage their psychosocial disabilities. The overarching reforms are presented in Figure 77, with further detail throughout this section.

Figure 77: Overview of the pathway for NDIS psychosocial supports
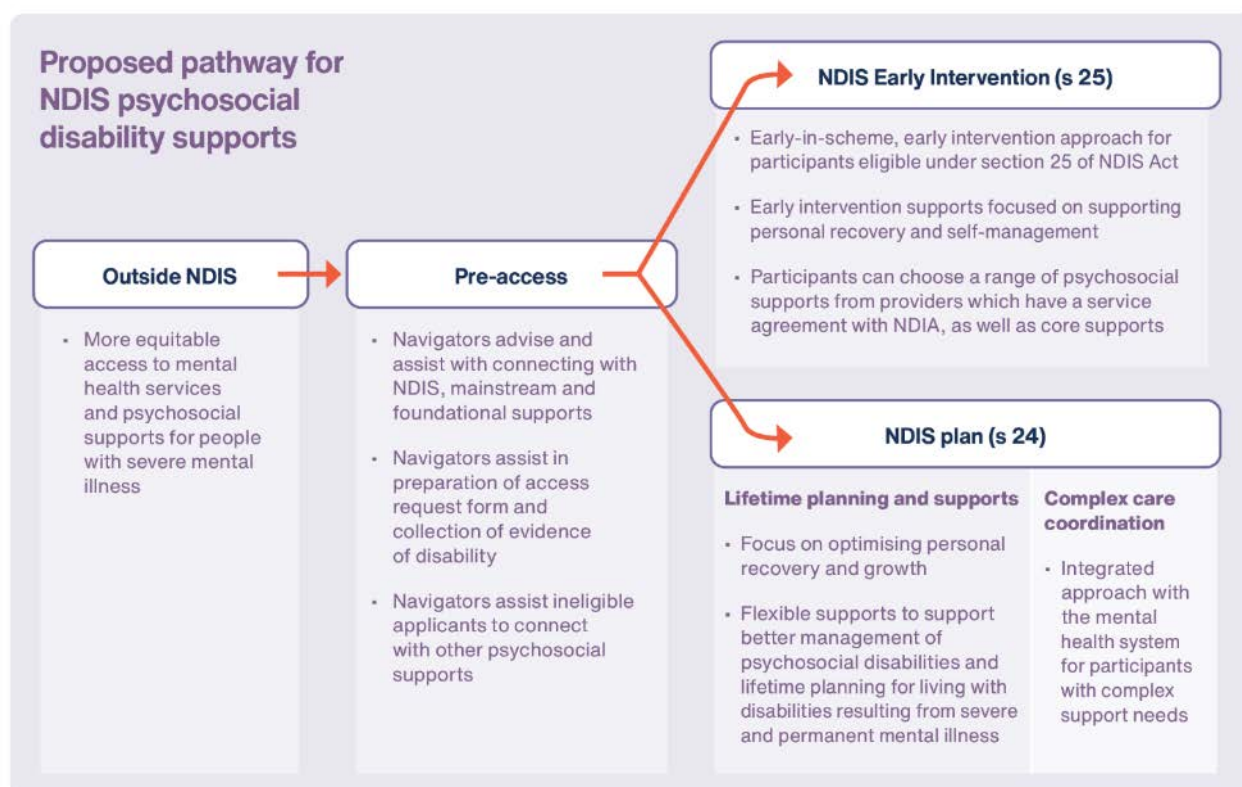
Navigator roles working with people with psychosocial disability

The NDIA should commission Psychosocial Recovery Navigators who are well trained, have experience and expertise in psychosocial disability and are trauma-informed to work with participants with psychosocial disability, who are in the scheme. Appropriate practice standards should be developed to reflect expectations of this role (see Action 7.4).

General Navigators should be available to provide information and connections for people with psychosocial disability who are interested in the scheme. General Navigators should also provide pro-active outreach for those people with mental illness experiencing barriers to accessing services. They should help people with severe mental ill-health to connect with the right services, including community mental health, foundational supports and the NDIS. This includes people who are homeless or disengaged with services. The outreach function should build on findings from the evaluation of the NDIS Community Connector Program (2020-21), including that outreach requires dedicated staff who have a good understanding of NDIS processes and psychosocial disability, and can build long-term relationships with people with psychosocial disability.[1037]

> *"I think someone should be able to ring up/or fill in an online form/or go into a local NDIS office and be able to say 'I need help'. From there I would like to see a caseworker assigned to that person who can go about arranging assessments at their home and in the community; contacting existing or previous health professionals who have treated this person and build a case from there." – Participant and carer[1038]*

"My 29 year old son lives with me but he will not seek any support for his mental health issues and after struggling for 15 plus years for him to get support I am too exhausted to get him to agree to apply to NDIS. I am 67 and am concerned re his future". – Carer[1039]

A clearer and more consistent approach to access

The NDIS should be focused on people with the most severe psychosocial disability, forming the upper end of a continuum of psychosocial supports. To do so, the NDIA should develop access criteria, in consultation with Australian, state and territory health systems, people with psychosocial disability, families, representative organisations, researchers, and mental health experts. It needs to be part of the broader approach to ensuring there is an ecosystem of support including support outside the NDIS, through the National Mental Health and Suicide Prevention Agreement[1040] and the new Disability Intergovernmental Agreement (see Action 20.1).

The introduction of an early intervention approach under section 25 (Early Intervention) of the NDIS Act will require the NDIA to publish guidance on the criteria and evidence for this pathway. Guidance will also be required on the transition process to eligibility under section 24 (Disability Requirements) of the NDIS Act, to ensure this transition is streamlined and straightforward. Once agreed through NDIS Rules, the NDIA should operationalise access criteria through published guidelines for health professionals, mental health services and applicants on eligibility and evidence requirements.

Better supporting participants to optimise their independence and self-management and participation in education and employment

NDIS budgets under section 25 and section 24 of the NDIS Act should be flexible, with participants supported to exercise choice and control.[1041] The Recovery Framework recognises that a recovery approach needs to be owned and led by the individual.[1042] As part of the overarching proposed reforms to budget setting and implementation (see Action 3.3-3.6), budgets would allow for flexibility in how participants choose to use their funds.

Budget setting should be based on a mix of evidence-based supports. It should consider participants' support needs on their days of higher support need (their bad days) and the frequency of higher support need days. It is important that budgets recognise the episodic nature of psychosocial disability.[1043] Budgets should be able to step up and step down in line with fluctuating needs, with rapid reviews to adjust support need levels up when an acute episode occurs, and down again after the participant is able to undertake daily living tasks again.[1044]

We heard from participants and carers that they need more assistance with navigating the NDIS.[1045] Navigators with psychosocial competencies would assist participants in setting and achieving their personal goals, identifying evidence-based supports, improving economic and social participation and connecting with mental health, primary care and social housing services.

"[A] specialist coordination team can provide holistic and recovery-oriented support with the expertise to assist participants with specialised treatment, care and services for psychosocial disability." – Australian Psychosocial Alliance[1046]

In 2020, the NDIS introduced a support item for psychosocial recovery coaches, to assist participants to design a recovery plan and coordinate NDIS and other supports.[1047] We have heard that the introduction of Recovery Coaches has been very positive. However, there is currently ambiguity about the roles of Recovery Coaches and support coordinators.[1048] The current Recovery Coach support item should transition into the Psychosocial Recovery Navigator role over the next few years.

As part of implementation, the NDIS should set out its approach to psychosocial disability supports and develop national practice guidelines

The new approach to psychosocial disability supports should be designed with people with psychosocial disability, families and carers, service providers, health professionals and researchers. This includes ensuring NDIS supports meet the needs of First Nations people with psychosocial disability.[1049]

As an overarching policy statement, the NDIA should provide guidance on how the NDIS will work with participants to help them achieve their personal goals and provide effective disability supports. This guidance would include approaches and practices for supports for participants; practice expectations for planning and navigation; identifying effective psychosocial interventions; and strategies for monitoring outcomes for participants with psychosocial disability.

The NDIA should also work with mental health services and NDIS providers to develop National Psychosocial Disability Practice Guidelines setting out best practice for recovery-focused supports for NDIS and non-NDIS services.

6.1.3. Action & Implementation Details

Action 7.1: The <u>National Disability Insurance Agency</u> should introduce a new approach to psychosocial disability in the NDIS based on personal recovery and optimising independence.

The approach should implement and build upon the NDIS Psychosocial Disability Recovery-Oriented Framework, including strengthening integration and working arrangements with the mental health system. Access and assessment processes should be tailored to the specific needs of participants with psychosocial disability and be delivered more consistently and equitably, including through an uplift in the capability of NDIS staff. Navigators and Specialist Navigators should have competencies in psychosocial supports to assist people to access evidence-based NDIS, mainstream and foundational services (see Action 4.1).

Implementation detail:

- The National Disability Insurance Agency should:

  - Implement the NDIS Psychosocial Disability Recovery-Oriented Framework.

  - Adopt the following objectives to guide the introduction of a more active approach to supporting participants with psychosocial disability:

    o build optimal independence
    o support personal recovery
    o maintain independence.

  - Through the NDIS Experience Design Office, develop guidance on how the NDIS will work with participants to help them achieve their personal goals and provide effective disability supports. This guidance would include approaches and practices for supports for NDIS participants; practice expectations for planning, navigation and direct supports; identifying effective psychosocial interventions; and strategies for monitoring outcomes for participants with psychosocial disability.

  - Work with mental health services and NDIS providers to develop National Psychosocial Disability Consensus Practice Guidelines setting out best practice for recovery-focused supports in NDIS and non-NDIS services.

  - Commission Navigators with psychosocial competencies and Psychosocial Recovery Navigators (see Action 4.1) to:

    o Conduct outreach and assist people with psychosocial disability to apply for the NDIS and/or connect with non-NDIS services.
    o Assist participants in setting and achieving their personal goals, identifying evidence-base supports, improving economic and social participation and connecting with mental health, primary care and social housing services.

  - Develop and provide clearer guidance on NDIS eligibility and evidence requirements for psychosocial disability. Improve the access assessment process to make it more sensitive to the particular needs of applicants with severe mental illness and ensure that ineligible applicants are linked into other sources of support.

6.2. An early intervention approach for psychosocial disability has not been developed

An early intervention approach for new participants with psychosocial disability who are likely to benefit from these supports would improve their functional capacity and quality of life, as well as improving the sustainability of the NDIS.

6.2.1. The lack of early intervention in the NDIS for participants with psychosocial disability is a missed opportunity to maximise their wellbeing

Section 25 of the NDIS Act enables the NDIS to provide early intervention supports for people with disability that is, or is likely to be, permanent, where these are likely to benefit the participant by

improving functional capacity. As described in Section 2.1.1, the current early intervention pathway remains unclear, except for children. The under-emphasis on early intervention supports across the scheme for adults likely to benefit, for example for people with neurological conditions, to improve outcomes and reduce the long-term impacts of disability, also affects participants with psychosocial disability.

The NDIS does not have an early intervention approach for participants with psychosocial disability. This means the scheme is not keeping pace with evidence of the advantages of psychosocial early intervention and is not adequately supporting participants to optimise their daily living and community participation skills, including in education and employment, and to focus on recovery. It is also contributing to higher than necessary long-term support costs.

> *"People with psychosocial disability can benefit from a range of early intervention options, delivered both through mainstream services and through the NDIS. It is important to note that early intervention does not necessarily mean interventions occurring early in life. Early intervention can also occur for example early in onset of symptoms or early in identification of particular risk factors occurring, throughout a person's life." – Mental Health Australia[1050]*

The evidence for psychosocial early intervention has grown significantly over the past decade. This evidence suggests that for some people with significant disabilities due to their mental health conditions, reductions in levels of disability can be achieved through use of evidence-based supports, addressing social determinants and strengthening personal motivation for improvement. It builds on people's motivation to be as mentally well as they can be and as independent as they can be.

Early intervention can be effective in reducing impairment, improving activity and strengthening informal supports.[1051] A 2016 literature review by the University of Melbourne found "significant evidence that people with psychosocial disability make significant gains in their capacity to engage in social and economic participation if they are offered early intervention". This literature review and more recent studies identify evidence-based supports as including social skills training, cognitive remediation, supported employment, illness self-management and peer support.[1052]

A further basis for early intervention for psychosocial disability is the significant impacts of social determinants of disability for people with severe mental illness. Social determinants such as trauma, stigma and discrimination result in social withdrawal and isolation, lack of educational opportunities and reduced informal supports. These are significant factors that contribute to severe psychosocial disabilities. The impacts of these determinants are variable. However, these social determinants can be addressed and their disability impacts lessened. For example, stigma and discrimination against people with serious mental illness has significant disabling consequences in terms of social isolation and demotivation for community participation and employment. It is socially created and can be addressed at individual and societal levels.

Many participants experiencing high levels of psychosocial disability have also not previously had access to sufficient mental health treatments and other psychosocial supports, due to cost, availability or barriers arising from mental illness or drug dependencies. A significant example of

this is that 58 per cent of NDIS participants with a primary diagnosis of psychosocial disability were not receiving funded disability supports at the time of entering the scheme (as of 30 June 2023).[1053]

The lack of an early intervention approach fails to recognise the potential for improvement in psychosocial functioning with the right supports. It presumes that the assessment of needs at entry to the scheme will be stable for the participant's lifetime rather than recognising the potentially positive impacts of evidence-based early intervention supports to improve quality of life and reduce levels of disability.

6.2.2. Establishing an early intervention pathway

As recommended in Action 3.7, the NDIA should reform the early intervention pathway for people with disability to get better outcomes and ensure participants receive more effective support targeted to their needs. Reforms to the early intervention pathway are consistent with the insurance approach of the NDIS - invest early to get better long-term outcomes for participants.

As part of this broader approach to early intervention, the NDIA should establish an early intervention pathway under section 25 of the NDIS Act, for new participants with psychosocial disability who are likely to benefit from early intervention supports. This pathway would be for participants who would benefit from timely access to the right mix of supports, to help improve functional capacities, support them to engage in education and employment opportunities and rebuild social connections. The NDIS would provide access to an innovative, evidence-based and flexible range of supports.

Given the potential for early intervention supports to help many people with psychosocial disability, this could be the pathway within the NDIS that best meets the needs of many new participants. That said, this pathway would not be appropriate for some new participants, particularly people with the most severe and complex support needs, who should access the NDIS through section 24 of the NDIS Act.

The NDIS early intervention pathway would provide supports to improve participants' functional capacities and promote recovery. It would also offer information, education and supports to carers and family. It would focus on getting to know participants and understanding their personal journey with psychosocial disability. The approach would help build participants' knowledge and skills in their lifetime planning for and management of their disability.

The early intervention approach should have a strong focus on personal recovery, focusing on information and supported decision-making to assist participants to choose the right supports. Participants would be able to work with a Psychosocial Recovery Navigator to select and use early intervention supports. Psychosocial Recovery Navigators would assist participants in setting up the goals they want to work on, help them to identify effective psychosocial interventions and support them to achieve their personal goals and approach to recovery. Building links with mainstream services such as mental health, primary health care, housing and alcohol and drug services, where relevant, would be a key part of the early intervention pathway.

The early intervention pathway is not a block funding model. Participants should have the flexibility to use their budget to choose from a range of approved psychosocial early intervention providers, as well as daily living supports. To offer early intervention supports in the market, providers should be required to enter a service agreement with the NDIA that specifies service delivery requirements aligned with evidence-based, recovery-focused approaches. Service agreements should facilitate integrated service provision and specify how services would be responsive to individual and changing needs. This would maintain participant choice, recognise the variation of participants' circumstances, and ensure providers have the skills, expertise and evidence-based approaches needed for effective supports.

> **Box 37: The individualised budget would be developed with the participant to meet their needs and preferences.**
>
> Early intervention would include a range of individually funded supports, complemented by foundational supports:
>
> - Comprehensive recovery planning
> - Provision of educational and personal development courses
> - Access to peer support
> - Family psychosocial education
> - Supported employment
> - Support to find and maintain housing
> - Access to online courses and self-development apps
> - Cognitive remediation
> - Professional services to improve daily living skills and health literacy
> - Daily living and community access supports
> - Social skills training

In the design and implementation of this approach, the initial focus should be on service standards and ensuring that organisations commissioned by the NDIA have the workforce and management with the required expertise and experience. Payments should be based on fee for service, at least initially. The outcomes from this early intervention approach should then be measured using metrics that have been tested and agreed with people with psychosocial disability, families, representative organisations and experts.

Depending on the evidence, consideration could then be given to a mixture of payment methods including enrolment and blended payments. However, any shift to enrolment and, especially, outcome payment methods would need to be carefully tested to ensure they did not have perverse effects and lead providers to cherry pick participants and not support those with more complex needs. This step should also not be taken without deep engagement with people with psychosocial disability, families, representative organisations and experts, so that the selected payment methods encourage use of evidence-based supports, creating incentives for providers to actively support a participant's recovery and capacity building.

NDIS early intervention should, where possible, be delivered in partnership with mental health and primary health care services, to facilitate a more integrated approach across the NDIS and mental health services. This may be through the NDIA and mental health services sharing information (with participants' consent) about supports being provided to participants in each system, and mental health services committing to providing treatment supports for participants in the early intervention pathway (see action 7.6).

Early intervention supports should be provided for up to three years. For some participants, NDIS early intervention supports may be sufficient. With such stabilising supports, they may not need to remain in the scheme on a continuous basis and would be assisted to connect with expanded foundational supports. However, if they need NDIS supports again in the future, streamlined arrangements should be in place for their re-entry to the scheme, which would generally be through section 24 of the NDIS Act. For many participants, a period of early intervention supports will not be sufficient, and they should have a streamlined transition to lifetime NDIS supports under section 24 of the NDIS Act.

The early intervention pathway should be designed with people with psychosocial disability, families and carers, service providers, health professionals and researchers. It would build on research and experience in psychosocial early intervention and recovery and trauma-informed practice in Australia and internationally.

When designing the details of the proposed early intervention pathway for participants with psychosocial disability, the priority must be maximising opportunities and prospects of personal recovery and the associated improvements in quality of life for this group, not any consequent reductions in scheme costs. Cost reduction should and cannot be the driver of these reforms. This is part of the Review's commitment to put people with disability back at the centre of the NDIS.

As noted earlier, not all new participants with a psychosocial disability will enter via the early intervention pathway. Those with the most complex support needs who are identified as having ongoing high support needs will continue to enter the NDIS under the permanent disability pathway (section 24 of the NDIS Act). There will be no change for this group.

How many people recover to the point where they no longer need the NDIS and how many improve, but still need the NDIS, is unclear. For the majority, who have ongoing support needs and enter the NDIS under section 24 of the NDIS Act, some will have lower support needs, because of the benefits of the early intervention approach. Others, despite best endeavours, will not have recovered sufficiently to change their support needs.

For those participants with psychosocial disability who enter the scheme under the early intervention pathway (section 25 of the NDIS Act) and then recover to the point that they no longer need the NDIS, it is possible that some may need to apply again for access to the NDIS, either under section 25 or section 24 of the NDIS Act. This should be allowed, as part of an approach that ensures people with psychosocial disability receive the supports they need while responding to the complexity and fluctuating nature of their support needs.

6.2.3. Action & Implementation Details

Action 7.2: The <u>National Disability Insurance Agency</u> should establish an early intervention pathway for the majority of new participants with psychosocial disability under section 25 of the National Disability Insurance Scheme Act 2013.

This should provide structured and targeted time-limited supports for a defined period of up to three years. It should deliver evidence-based psychosocial early interventions including supported employment, supports to find and maintain housing, illness self-management, cognitive remediation, family psychosocial education and social skills training. Participants should be able to choose from a range of providers, which have entered into a service agreement with the National Disability Insurance Agency (NDIA) that sets specific service delivery requirements. Following the early intervention period, Navigators should assist people who no longer need NDIS supports to transition to mainstream or foundational services, or if ongoing NDIS supports are required, transition to NDIS supports under section 24 of the NDIS Act.

Implementation detail:

- The National Disability Insurance Agency should:

    - Develop an early intervention pathway for NDIS participants under section 25 of the NDIS Act. This design process would need to meet the criteria in section 25 and demonstrate that these supports could prevent the deterioration of, or improve, participants' functional capacities.

    - Design an early intervention approach in which participants can choose a range of psychosocial supports, as well as daily living supports. This would include supports such as education and personal development courses, peer support, online courses and self-development apps, social skills training, professional services to improve daily living skills and health literacy, and daily living and community access supports.

    - Require providers of early intervention psychosocial supports to be registered, including demonstrating compliance with support-specific Practice Standards (see action 7.4). In addition, providers should be subject to a service agreement contract defining specific service delivery requirements of the early intervention approach. Service agreements should include a focus on building strong communities of practice among service providers and developing a learning model which improves service delivery.

    - Provide early intervention supports to participants for up to three years, based on individual requirements. If the program mitigates, improves or prevents the deterioration of their functional capacities to the extent that they no longer meet the disability criteria, Psychosocial Recovery Navigators would support

> participants to transition to non-NDIS psychosocial supports, available through enhanced foundational supports, and exit the scheme. If their needs change in future, they should be able to re-enter the NDIS, which would generally be under section 24 of the NDIS Act. If early intervention does not change the permanency of their psychosocial disability, participants would be supported to make an application for entry to the scheme under section 24 of the NDIS Act.
>
> - Offer this early intervention program to participants who meet eligibility criteria approved by the NDIA Chief Executive Officer. Participants entering the NDIS under section 24 of the NDIS Act could also choose to use the early intervention supports if participants consider these supports would be beneficial.

6.3. For participants with highly complex needs, the NDIS is not providing intensive, coordinated assistance

As described in Chapter 1, some participants have complex needs due to a combination of disability and situational factors. The NDIS does not support people with psychosocial disability and highly complex needs well. This results in worse outcomes for participants, and greater pressure on hospitals and the NDIS, compared to what could be achieved through a more integrated approach across the NDIS and mental health system.

6.3.1. NDIS is not working well for people with complex needs

Approximately 3,000 participants with psychosocial disability have a level of funding equivalent to requiring 24/7 living supports at a 1:3 support ratio or above (as at 30 June 2023).[1054] These participants have the most complex support needs and require intensive mental health and disability supports, delivered by specialised staff due to significant behavioural management and risk management issues. Some people in this group of participants have been discharged from long stays in hospital, have co-occurring conditions, and cycle through Emergency Departments, short-stay hospital admissions and homelessness services. Some participants have been subject to correctional and forensic services.

The NDIS provides significant funding for some participants with complex needs. For example, total NDIS expenditure for the 3,599 participants with psychosocial disability and supported independent living (SIL) supports is $1.2 billion per annum (as at June 2023). This is approximately 27 per cent of NDIS expenditure for psychosocial disability supports.[1055] The mental health system also invests considerable resources in supports for this group of participants. The NDIS and health systems have improved system interfaces over the past few years. The introduction of health liaison officers improved hospital discharge practices between the NDIA and hospital staff. The NDIA also supports participants with complex needs through its Complex Support Needs Pathway.

Overall, however, the NDIS is not providing the level of coordinated care required, particularly with the mental health system. Current arrangements result in no clear responsibility for monitoring

how a participant's placement and transition plan for community living is going and responding to early signs that support plans are starting to break down or that a participant's support needs go beyond the capacities of their service providers. The NDIA does not play an active role in monitoring services. While the NDIS Quality and Safeguards Commission is responsible for addressing complaints and critical incidents, it does not have responsibility or resourcing for ongoing monitoring and management of complex supports or Positive Behaviour Support Plans (see Chapter 5).

Generally, neither the NDIA nor hospitals have information about how a participant's plan is going until difficulties arise. Often, at this point, it is too late to intervene to prevent the placement breaking down and the participant being readmitted to hospital. Alternative support plan arrangements generally take some time to organise, given the service skills and risk management issues involved. This increases use of emergency department and hospital beds.

> *"People with severe mental health issues should never be released from a psychiatric ward without wrap around supports (supported independent living with decreasing intensity over time according to improvement/needs)." – Participant and carer[1056]*

In addition, support coordinators and Recovery Coaches working with these participants sometimes do not have the required specialist knowledge and access to multi-disciplinary advice needed for effective management of complex support needs.

Without a dedicated and coordinated approach across the NDIS and mental health system, participants often do not receive the complex and consistent rehabilitation and disability supports required to support people living in the community. This means participants have lower levels of improvements in mental health and reductions in functional impairments than could be achieved through a coordinated approach. Participants are more likely to experience unnecessarily long stays in hospital, inadequate supports to transition and live safely in the community, and frequent readmission to hospital and prison.

Poor coordination results in poor outcomes for participants and impacts NDIS and mental health system costs. An example of this is the use of acute mental health beds by long-stay patients in public hospitals. As of June 2023, there were approximately 443 participants with psychosocial disability who were resident in public hospitals for more than twelve months, using an estimated 160,000 bed days at a cost of $211 million to the public hospital system.[1057] The lack of service providers with appropriate skills to support these participants causes delays to hospital discharges and can result in relinquishment of support plans by providers, leading to participants being readmitted to hospital.

State and territory governments have developed programs such as the NSW Pathways to Community Living Initiative to manage complex mental health and disability support needs.[1058] Generally, these initiatives involve shared protocols, multi-party teams and integrated planning. These initiatives highlight that better outcomes and reduced costs can be achieved through integrated and coordinated mental health and disability supports.

6.3.2. Shared planning and funding for co-ordinated complex treatments, rehabilitation and disability supports for participants with psychosocial disability

Across the scheme, there should be a priority work program to improve coordination between complex mainstream settings and the NDIS (see Action 2.7). An element of this work program should be establishing an integrated complex coordination approach with the public mental health system for participants with complex mental health treatment and disability support needs.

The NDIA should develop Memoranda of Understanding (MoUs) that include the joint management of mental health treatment and disability supports between the NDIS and public mental health systems. This coordinated approach would provide for greater monitoring and timely intervention if a participant's plan begins to break down, for example, to develop alternative arrangements. It would provide a team approach involving participants, family and carers, the NDIA and mental health providers. This will require more flexibility in the ways in which the NDIA works with the public mental health system to meet the needs of individuals and increased joint planning.

Once negotiated through MoUs and intergovernmental agreements, it is critical this approach be practically implemented on the ground, for example, in collaboration between the NDIS and regional hospital and health systems. As part of this approach, the NDIA should build staff competencies in complex disability support management, both within the NDIA and, working with the Department of Social Services (DSS) and the new National Disability Supports Quality and Safeguards Commission, in the NDIS market (see Action 7.4).

6.3.3. Action & Implementation Details

Action 7.3: The <u>National Disability Insurance Agency</u> should establish an integrated complex care coordination approach with public mental health systems for participants with complex needs.

The integrated complex care approach should be a joint initiative between the NDIS and public mental health systems for participants with complex support needs and active mental health management issues. This should aim to facilitate effective and timely coordinated care to best meet the needs of participants and reduce lifetime support costs within the NDIS and mental health system. The approach should prioritise participants who have been long-stay patients in hospital, have co-occurring conditions, been released from prison and forensic services, and/or with complex behavioural management issues that require an integrated treatment and disability support approach (see Action 2.7).

Implementation detail

- The National Disability Insurance Agency should:

    - Develop, with state and territory governments, a proposal for the establishment of a complex care and disability supports approach between the NDIS and the public mental health system at regional, state and territory levels. This approach would be available for participants with complex mental health and co-occurring clinical disorders, resulting in

the need for shared and integrated complex care rehabilitation and specialised disability supports. It would prioritise participants who have been long-stay patients in hospital, multiple disabilities including psychosocial disability, been released from prison and forensic services, and/or with complex behavioural management issues that require integrated treatment and disability support across the NDIS and mental health services.

- Negotiate with state and territory governments for in-principle agreement to such a shared approach under the proposed Disability Intergovernmental Agreement, Memoranda of Understanding, and the National Mental Health and Suicide Prevention Agreement.

- Jointly design this approach, roles and responsibilities and operating guidelines and implementation timelines with state and territory governments. This would require coordinating and refocusing existing resources used by state and territory governments and the NDIS. Flexible use of resources and specialised training would be required to develop such specialised approaches.

- State and territory governments should:

- Expand the use of step-up, step-down residential facilities and mental health residential services in transitioning participants with complex care requirements to community living.

6.4. Psychosocial disability competencies need uplifting

6.4.1. The NDIS is not stewarding the market to deliver a recovery-focused approach

We heard concerns from participants and providers that there are too few providers with sufficient understanding of mental health care.[1059]

> "In my experience, good support workers are few and far between, especially within the psychosocial space. Support work needs to be regulated. Anyone can be a support worker and that's dropping the standard. To work within mental health, you should have to have qualifications, experience and supervision." – Participant[1060]

> "NDIS planner and services having limited understanding or training with psychosocial disabilities leading to further trauma for participants and family. … No understanding of comorbid psychosocial disabilities, especially schizophrenia plus numerous other disabilities presenting at the same time. Service providers saying they have mental health experience but in reality see themselves as a baby sitting service with no intention of following clinician recommendations." – Carer[1061]

These problems with workforce supply are resulting in participants not receiving recovery-oriented and trauma-informed supports. As the Mental Health Commission of NSW noted, "workers have been reported to 'do (tasks) for' participants as opposed to 'do with' or 'empower to do'".[1062] Without training in mental health, providers may not have critical skills such supported decision-making and de-escalation.[1063]

6.4.2. The NDIS should better use and increase the supply of providers with psychosocial expertise

There should be a focus on building psychosocial competencies in the service provider market. The NDIS should continue to fund core daily living support, but participants would also have access to more providers and therapists who have the competencies to help people achieve their personal goals and build and maintain their independence.

As part of the broader framework for provider regulation (Action 17.1), the new National Disability Supports Quality and Safeguards Commission should develop a support-specific Practice Standard for the delivery of psychosocial disability supports. The Practice Standard would apply to Psychosocial Recovery Navigator, psychosocial early intervention, capacity-building and 24/7 living supports for participants with psychosocial disability. This should be undertaken in conjunction with an early focus by the new Deputy Commissioner for Quality (Action 12.1) on driving quality in the delivery of psychosocial supports.

The Practice Standard should define expectations of providers in the delivery of a recovery-oriented and trauma-informed supports, psychosocial-specific safety and quality expectations, including post-crisis and post-intervention and preferred and minimum staff psychosocial competencies for the delivery of psychosocial disability specific-supports. Participants, families and carers, representative organisations and researchers should be involved in the development of these standards.

The Practice Standards should be developed with reference to the National Safety and Quality Health Service (NSQHS) Standards for mental health services and the NDIS Psychosocial Disability Recovery Oriented Framework. For providers accredited under the Mental Health Standards, mutual recognition should also be built into the system to reduce regulatory burdens.

As part of market stewardship, the NDIA and DSS should increase the supply of providers who can meet these new requirements. This includes working with the Department of Employment and Workplace Relations on training (such as micro-credentials) and vocational education and training (VET) initiatives. This should include working with HumanAbility, in its capacity as the relevant Jobs and Skills Council for the care and support sector.

Mental Health Victoria, with funding from the Department of Social Services, has developed a range of proposals for building the provider market's capacity to deliver recovery-oriented supports. This includes proposals for online micro-learning, a digital information hub, ensuring pricing enables reflective supervision, and supporting communities of practice.[1064]

To draw on expertise in the mental health system, the NDIA should encourage organisations with a focus on people with severe and permanent mental illness – such as public mental health services, non-government organisations, health professionals, primary care services, private psychiatric hospitals and workers' compensation insurance providers – to apply to provide navigation and early intervention services.

"A sustainable funding approach will enable higher-quality support and opportunities for capability-building within the workforce." – Australian Psychosocial Alliance[1065]

There should also be a review of pricing arrangements to ensure they are sufficient to retain and attract psychosocially competent providers to the NDIS market. As described in Chapter 4, there are a range of payment methods (such as enrolment, outcomes-based and blended payments) which can be used if necessary to support an effective market.

6.4.3. Action & Implementation Details

Action 7.4: The new <u>National Disability Supports Quality and Safeguards Commission</u> should require providers delivering psychosocial supports to be registered, including demonstrating compliance with a new support-specific Practice Standard.

This Practice Standard should set out additional responsibilities of providers when delivering psychosocial disability-specific supports, including workforce competencies (see Action 17.1). These requirements would apply to Navigation, early intervention, 24/7 living supports and capacity-building supports for participants with psychosocial disability. This should be complemented by market stewardship by the National Disability Insurance Agency (NDIA), the Department of Social Services (DSS) and the National Disability Supports Quality and Safeguards Commission, including investing in training in psychosocial supports. As part of a broader proposed role in advising on pricing (see Action 11.3), the Independent Health and Aged Care Pricing Authority should also develop updated payment approaches and advise on price caps for psychosocial disability-specific supports.

Implementation detail:

- The new National Disability Supports Quality and Safeguards Commission should:

  - Require providers of psychosocial support services (Psychosocial Recovery Navigators, psychosocial early intervention, capacity building and 24/7 living supports for participants with psychosocial disability) to be registered and meet a new support-specific Practice Standard.

    o The new psychosocial support-specific Practice Standard should be developed with consideration to principles in the National Safety and Quality Mental Health Standards for Community Managed Organisations and the NDIS Psychosocial Recovery-Oriented Framework.
    o Participants, families and carers, representative organisations and researchers should be involved in the development of these standards.

- The NDIA and DSS should:

  - In collaboration with the Department of Employment and Workplace Relations and Department of Health and Aged Care, invest in training programs in

recovery-focused psychosocial support provision, including funding the development and refinement of micro-credentials.

- Work with the relevant Jobs and Skills Council, HumanAbility, as well as professional bodies and education providers to better align vocational education and training (VET) programs with the skills needed for recovery-oriented psychosocial supports.

- Seek to diversify the market of service providers with existing psychosocial capacities through encouraging mental health services and workers' compensation insurance providers to become providers of specialist NDIS psychosocial support services.

- The Independent Health and Aged Care Pricing Authority should, as part of its new pricing role for the NDIS, review current pricing for specialist psychosocial support services to ensure pricing is sufficient to attract and retain psychosocially competent service providers, once updated Practice Standards and service agreements have been developed.

6.5. Foundational supports for psychosocial disability can be used more effectively

As described in the Chapter 1, governments should expand foundational supports for all people with disability (see Action 1.3). There are some evidence-based supports for people with psychosocial disability that are currently underutilised by the NDIS and could be funded through general foundational supports. In addition, there is a significant gap in psychosocial supports for people with psychosocial disability outside the NDIS, which should be addressed as part of mainstream community mental health reforms (see Box 38).

> **Box 38: Targeted foundational supports: there is a significant gap in psychosocial supports outside the NDIS**
>
> Psychosocial supports are non-clinical services that assist people with psychosocial disability to build personal capability and stability in areas such as relationships, day-to-day living skills, housing, education and employment. Psychosocial supports are a joint Australian, state and territory government responsibility.[1066] Current services are primarily administered by Australian, state and territory government mental health systems, and delivered by non-government organisations.
>
> Notwithstanding existing support programs, many people with psychosocial disability are missing out. In 2020, the Productivity Commission estimated that of the 290,000 people with severe and persistent mental illness, 154,000 people were unable to access psychosocial support services.[1067] The Productivity Commission estimated that expanding psychosocial support to cover those missing out would require an additional $610 million per annum.[1068]

In 2022, under the National Mental Health and Suicide Prevention (NMHSP) Agreement, jurisdictions agreed to work together to develop future psychosocial support arrangements for people who are not supported through the NDIS.[1069] The Australian, state and territory governments are conducting a gap analysis of existing programs which is due for completion by March 2024. Governments have committed to develop a future approach, as a schedule to the NMHSP Agreement.

As set out in Action 1.11, National Cabinet should agree to expand psychosocial supports outside the NDIS to assist people with severe and persistent mental ill-health currently unable to access supports. See Chapter 1 for further details.

6.5.1. There are some evidence-based supports that should be available for all people with psychosocial disability

There are several supports which have a strong evidence-base, including:

- *Family psychosocial education initiatives:* Programs to help family members and carers to improve their understanding of severe mental ill-health, resolve problems, and learn approaches to support people with psychosocial disability.[1070]
- *Mental health lived experience and peer worker initiatives:* Programs to build mutual mental wellbeing support networks.
- *Recovery Colleges:* Centres for people with mental-ill health, family members, clinicians and providers to learn about mental health, through education programs which they can attend and contribute to developing.[1071] There are several existing recovery colleges in Australia.[1072]
- *Digital psychosocial supports:* There is good evidence that many people with psychosocial disability prefer to use online supports, including due to the anonymity they offer.

6.5.2. Action & Implementation Details

Action 7.5: <u>All Australian governments</u> should prioritise supports for people with psychosocial disability as part of general foundational supports.

This should fund a range of initiatives providing information, individual and family capacity-building. Priority areas for investment include mutual peer support; recovery colleges where people can learn about mental health; and family psychosocial education to assist families in their roles of supporting people with severe mental ill-health. In addition, as a targeted foundational support, governments should commit to increasing supply of psychosocial supports outside the NDIS (see Action 1.11).

Implementation detail:

- The Australian Government should make psychosocial supports a priority area within general foundational support programs (see Action 1.3). Priorities for investment include:

  - Peer support programs, to build mutual mental wellbeing support networks.

  - Recovery colleges, where people with mental ill-health, family members, clinicians and providers can learn about mental health.

  - Family psychosocial education, to help family members and carers improve their understanding of severe mental ill-health, resolve problems, and learn approaches to supporting people with psychosocial disability.

  - Digital psychosocial supports, noting digital services can be effective and are currently underutilised within the NDIS.

6.6. The NDIS does not operate effectively with the broader mental health system and there are barriers to accessing treatment

Many participants, particularly people with psychosocial disability, need access to mental health services but cannot access them due to cost and availability factors, impacting their wellbeing and increasing reliance on NDIS supports. In addition, the NDIS and mental health systems are siloed at a policy and operational level. Significant reform is underway in the mental health system (see Box 39). Under the National Mental Health and Suicide Prevention (NMHSP) Agreement, governments should build on these reforms to increase access to mental health treatment for people with disability and set out agreed strategies to increase collaboration and cooperation between health and disability systems.

Box 39: Mental health reforms

There are several reforms underway, including:

- The National Mental Health and Suicide Prevention Agreement includes new funding for community mental health services, including Head to Health Adult Mental Health Centres and Headspace.[1073]
- Significant mental health reforms in Victoria, in response to the Mental Health Royal Commission, will consolidate funding into integrated Local and Area Mental Health Services, for both clinical and psychosocial supports.[1074]
- The Mental Health Reform Advisory Committee, established by the Australian Government Minister for Health and Aged Care, is advising on mental health reforms, including in response to the *Better Access initiative* evaluation.[1075]
- The Social and Emotional Wellbeing Policy Partnership, chaired by Gayaa Dhuwi (Proud Spirit) Australia and the Department of Health and Aged Care, is developing a joined-up approach to First Nations social and emotional wellbeing and mental health.[1076]

- The Australian Mental Health Care Classification system for public mental health service funding includes provision of psychosocial supports within public community mental health services.[1077]

6.6.1. Mental health services are often unavailable or unaffordable

Availability and affordability are significant barriers to accessing mental health treatment. For example, psychiatry and psychology services have high out-of-pocket costs, which particularly impact people with chronic conditions and low incomes.[1078] In 2021, 65 per cent of Medical Benefits Scheme (MBS) Better Access treatment services had a co-payment. In first half of 2022, the median co-payment was $90 for an MBS Better access treatment session.[1079]There is a shortage of community mental health services in-between general practices (GPs) and specialised state and territory mental health [1080] as well as inadequate specialists and waitlists in some. [1081] Rehabilitation for mental illness prior to hospital discharge is inconsistent.

> "10 discounted sessions is not enough for someone with complex mental health needs this leads to increased suicide rates, depression, anxiety reduced ability to function in society" – Carer[1082]

> "In the world of psychosocial disability, psychiatry isn't bulk billed and despite Government saying that it's readily available through the state health care system, it's simply not." – Participant[1083]

> "Organisations part of the consultation spoke at length about the issues with: getting a mental health diagnosis; NDIS and other Mental Health agencies not knowing who is responsible for what … Often a counsellor or other dedicated mental health support is not available for ongoing case management." – First Peoples Disability Network[1084]

> "I can't afford the assessment or medications for ADHD. I can't even get a psychiatrist at the moment. This will mean I soon can't get my medication for my bipolar disorder. People might have a disability that would respond to treatment and get considerably better but can't afford the treatment without NDIS." – Participant[1085]

This can leave participants in a situation where they can access NDIS funding but cannot afford psychology or psychiatry services.[1086] The lack of availability and affordability of mental health services is resulting in many participants with mental ill-health.[1087] Combined with the gaps in the support of non-NDIS psychosocial supports, this is resulting in preventable or more severe psychosocial disabilities. These barriers to treatment also affect participants with multiple disabilities including mental ill-health.

6.6.2. While mental health and psychosocial supports are interdependent, the NDIS is artificially siloed from the health system

Supports for people with mental ill-health and psychosocial disability are delivered across the health and disability systems. However, these different types of supports are tightly interdependent and related. Indeed, the largely artificial siloing of clinical and psychosocial care is a failing of the current service ecosystem.[1088]

NDIS supports for people with psychosocial disability significantly impact, and are impacted by, the operations of the public and private mental health systems. NDIS expenditure on participants classified by the NDIA as having a primary psychosocial disability was approximately $4.3 billion in 2022-23.[1089] In comparison, total funding for mental health in Australia, excluding the NDIS, was $11.6 billion in 2020-21.[1090] The significance of the interdependencies between these two large national service systems is not reflected in national policy frameworks or inter-governmental agreements.

At the policy level, governments need to look at the balance of investment across mental health and NDIS systems, if a more efficient and responsive service system is to be achieved. Lack of investment in mental health services through Medicare and community mental health will result in escalating NDIS costs. Another example of this issue is the use of acute mental health beds by long-stay patients in public hospitals. The lack of a joined-up approach across policy and practice in both systems is resulting in poorer participant outcomes and reduced productivity in the public hospital system.

In applied principle four of the 2015 *Applied Principles and Tables of Support* (APTOS), the Council of Australian Governments directed that the NDIS and the mental health system to work closely together at the local level to plan and coordinate streamlined care for individuals requiring both mental health and disability services.[1091] Almost eight years on, this has not been tried (see Chapter 1 on APTOS and Chapter 6 on a new Disability Intergovernmental agreement).

The APTOS principles are dated and do not reflect the contemporary service delivery arrangements of mental health services. For example, they do not recognise the important role of private mental health services, nor the impacts of co-payments on accessibility. The NDIA does fund clinical mental health services on a limited basis, where their purpose is improving functional capacity. They do not fund mental health treatment services, which are the responsibility of the mental health system. For example, in the year to 30 September 2023, 34 per cent of participants with primary psychosocial disability claimed psychology supports (those who did claimed $3,268 on average).[1092] Further, the artificial split in the APTOS between psychology services provided under MBS and those under the NDIS makes little sense. The MBS cap of ten annual sessions with a psychologist under the Better Access program is unlikely to meet the needs of people with significant psychosocial disability.[1093]

The mental health system is changing rapidly in some states and territories, in response to mental health reforms. Levels of support and work practices vary across states and territories and in Primary Health Networks. NDIA planners and Local Area Coordination Agencies are not given

regular updates to assist them to stay up to date with these changes in mainstream mental health service provision.

Mainstream mental health services continue to evolve. An example of this is the significant roll out of Head to Health Centres, delivering community mental health and non-NDIS psychosocial supports. These Centres are generally delivered by non-government organisations and commissioned by Primary Health Networks.

The NDIA needs to keep its staff better informed about this changing landscape of mental health service provision to assist them in their roles. Another example, in Victoria, is the new Area Mental Health and Wellbeing Services. This new service model integrates psychosocial and clinical supports and often delivers a range of services through shared centres. People in Victoria's ongoing treatment, care and support streams will receive mental health services from them while they are also receiving support from the NDIS.[1094] These will be centres of psychosocial and mental health competency, connected to local communities. Such service delivery is opening more opportunities for integration, collaboration and coordination that the NDIA should participate in.

At the operational level, many public and private mental health providers are unaware of APTOS and intergovernmental program responsibilities (see Chapter 1 for a detailed assessment of APTOS and Action 2.6 for the new multilateral schedule to replace the APTOS). NDIS planners and partner organisations generally do not have good visibility of a participants' plan. Mental health, hospital and general practice service providers frequently raise concerns that they do not have information about the NDIS services being used. The lack of protocols, suitable privacy arrangements and data sharing arrangements is a barrier to more efficient, effective and co-ordinated service provision.

6.6.3.   The mental health system is currently being reformed

There are several reforms underway to improve the availability, operation and coordination of mental health services. These include recently commenced initiatives by the Australian Government Ministers for Health and Mental Health, implementation of recommendations from the Victorian Royal Commission, and response to the Queensland Parliamentary Inquiry into Mental Health.[1095]

However, Disability Ministers have limited involvement in the design and implementation of mental health reforms. As a result, there is no overarching approach to psychosocial supports. The NDIA is not involved in mental health policy reform development at national, state and territory levels and currently has limited capacity to engage in policy analysis of the impacts on NDIS participants and operations, or stay up to date to assist participants with navigating services.

6.6.4.   Governments should build on these reforms to prioritise access to mental health services for people with psychosocial disability

The future state involves Australian, state and territory governments jointly recognising that effective management of psychosocial disability requires both NDIS disability supports and mental health services being delivered in a coordinated and integrated manner through the respective responsibilities of both systems. Building on existing reform processes, the overarching objectives for governments should be to:

- Increase access to mental health care for people with disability, including people with psychosocial disability.
- Increase early intervention for young people experiencing recurring episodes of acute mental illness, which is vital to improving outcomes and reducing the need for future NDIS supports.

Governments should negotiate an integrated, cross-government approach to psychosocial disability under the NMHSP Agreement. This should include data collection on the provision of mental health treatment to people with psychosocial disability prior to, and concurrent with, NDIS supports. Disability Ministers, DSS and the NDIA should be involved in these reforms. This should include NDIA investing in its capability and operations to contribute to broader mental health reforms, and inform its staff, partners and service providers of the outcomes. This approach should also be reflected in the new Disability Intergovernmental Agreement (Action 20.1).

6.6.5. Reforms should also improve integration of mental health and disability services

NDIA should agree MoUs with state and territory mental health services, including plans for working together better in each jurisdiction. As part of a multilateral schedule to the new Disability Intergovernmental Agreement to replace APTOS (see Action 2.6), interface arrangements should be developed and mechanisms for monitoring implementation agreed. These MOUs should include arrangements for NDIS participants receiving priority access to mental health treatments, when their mental health conditions begin to become more acute.

Part of the role of Psychosocial Recovery Navigators should be to help connect participants with mainstream mental health services and seek updates from health providers. With the participant's consent, a description of the NDIS supports in their individualised budget should be shared with health providers to help build awareness of supports being delivered across systems.

6.6.6. Action & Implementation Details

Action 7.6: All Australian governments should improve access to mental health services for people with severe mental illness and strengthen the interface between mental health systems and NDIS.

Governments should update the National Mental Health and Suicide Prevention Agreement to set out an overarching approach to psychosocial disability supports to improve the integration and co-ordination of the NDIS and mental health systems. This should include: reforms to prioritise treatment for participants with psychosocial disability; early interventions to prevent and reduce the disability impacts of serious mental illness; and improving access to mental health services for participants more broadly. The NDIA and state and territory governments should develop Memoranda of Understanding to operationalise the approach to psychosocial disability supports (see Action 2.6), such as those agreed in the National Mental Health and Suicide Prevention Agreement.

Implementation detail:

- The Australian, state and territory governments should build on existing mental health reforms to develop a more integrated approach to supports for people with psychosocial disability:

  - Involve Disability Ministers and the NDIA in contributing to the development of mental health reform under the National Mental Health and Suicide Prevention Agreement and implementation plans.

  - Set out an overarching approach to psychosocial disability supports through the NMHSP Agreement and proposed new Disability Intergovernmental Agreement.

  - Establish Memorandums of Understanding and working arrangements with the Australian Department of Health and Aged Care and state and territory government mental health services for participants with psychosocial disability.

  - Clarify the respective eligibility requirements and coverage of NDIS and non-NDIS programs, to create a continuum of psychosocial supports.

  - Work towards the NDIS and mental health systems using consistent tools for the measurement of psychosocial disability, where appropriate.

  - Prioritise the provision of mental health treatment services to people with psychosocial disability prior to, and concurrent with, NDIS supports, including rapid access to public mental health treatment when NDIS participants are becoming acutely unwell.

  - Broaden data collection and reporting to include data on access to mental health treatment for people with psychosocial disability, including NDIS participants.

  - Expand services in key areas such as early intervention programs for young people experiencing recurring episodes of acute mental illness.

  - Encourage arrangements for delivering NDIS supports such as navigation and early intervention through mental health services.

Chapter 3: Housing and living supports

1. Key messages

- Achieving better housing and living outcomes for participants is critical to the scheme delivering on its promise of greater inclusion for people with disability and connection to family, friends and community.
- We recommend a package of reforms that will move the scheme towards a future vision for housing and living supports that delivers better outcomes for participants and is sustainable (see Box 40). At the heart of these changes will be a shift away from group home settings, to one where participants always have a say about their living arrangements and the supports they receive, in line with community norms and within the bounds of their allocated budget.

Housing and living supports that are fair, consistent and promote choice

- Housing and living supports are currently allocated in a way that is inconsistent, inequitable, and unsustainable. Participants with similar levels of function and circumstance do not always receive similar levels of funding, and they do not have access to the information, advice and support they need to make genuine informed choices on where, how and with whom they live.
- A new clear, consistent and transparent process for allocating housing and living support budgets is needed, complemented by Housing and Living Navigators to assist participants to explore their options and implement their budgets.

A more diverse and innovative range of inclusive housing and living supports

- Despite good intentions when the scheme was introduced ten years ago, there has been limited change and innovation in the way housing and living supports are provided. Outdated congregate care settings still dominate and the Specialist Disability Accommodation (SDA) market is not always delivering the right houses in the right locations.
- A wider range of housing and living supports that are better tailored to the diverse needs and circumstances of participants is needed. This would enable the NDIS to deliver on its promise of supporting the social and economic participation of people with disability, promoting better inclusion and outcomes, and giving participants genuine choice. Achieving this will require more effective market stewardship and intergovernmental collaboration.

Box 40: Vision for delivering housing and living supports in the NDIS

- NDIS participants receive housing and living funding amounts in a clear, fair and consistent way, in line with their needs and circumstances.
  - This should ensure that participants with similar levels of need, in similar circumstances, have access to similar levels of funding.
- Participants are supported to exercise genuine choice and control over where, how and with whom they live
  - While 24/7 living supports are generally funded on a shared basis of 1:3, no one should be forced to enter a living arrangement that is not of their choosing. A greater diversity in housing stock that allows individualised living with sharing of supports should be

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available to choose from. All participants, including those with cognitive impairment or limited support from family and friends, should have access to the information and expert, independent advice and assistance they need to explore housing and living support options, within the bounds of the budget allocated to them.

- The capacity of families and participants to explore and decide on housing and living support arrangements through key life transition points should be actively developed from an early age.

- There are a range of diverse and innovative options for participants to choose from to suit their particular needs and circumstances, that all embed a move away from outdated congregate care models.

  - All options, whether they involve sharing of supports or not, should feature:

    o Connection to the community — a place to call home, with inclusion in the community and opportunities for social and economic participation
    o Feeling safe — effective quality and safeguarding arrangements are in place, all of which support the development of informal supports which act as a natural safeguard
    o Good house design — that facilitates best practice delivery of supports and sustainability
    o A focus on quality in the supports delivered in the home — that recognises independence and continually build capacity
    o Access to the right mix of quality supports — including appropriate investment in supportive assistant technology and home modifications, as well as supports that sustain engagement of informal supports.

- Providers have the right incentives to innovate and offer diversity in housing and living solutions.

  - The SDA market should be flourishing, with the right stock in the right locations.

  - Pricing and regulatory settings should uphold quality and encourage evidence-based, best practice service delivery.

- Housing and living supports are delivered in a financially sustainable way.

  - Living supports should build capacity, reducing the need for funded supports where appropriate.

  - The cost of different housing and living models should be commensurate with the needs of participants.

- Governments work together to ensure access to mainstream housing support.

  - Participants without SDA should have access to suitable mainstream housing supports.

  - Arrangements for intergovernmental cooperation are used to hold governments to account for delivery on housing outcomes for NDIS participants.

2. Housing and living supports in the NDIS

* Good housing and living supports are crucial to enabling participants to live an ordinary life. They are the foundation of social, economic and community participation.
* The scheme currently funds a range of housing and living support which, combined, account for around a third of total scheme spending.

2.1. Why are housing and living supports important?

Having a place to call home is fundamental to our wellbeing and sense of belonging. Safe, secure and affordable housing is more than simply shelter — it provides the foundation for our participation in social and economic life in the community, fosters independence and guarantees dignity and privacy.

Better housing reduces costs and provides better living outcomes for people with disability.[1096] Research suggests that "well-located housing with appropriate design, technology, and support provision can make a significant contribution to improved health, wellbeing, increased independence, and reduced lifetime care costs for people with disability and complex care needs".[1097] A lack of access to affordable, secure and appropriate housing can, on the other hand, result in negative outcomes including homelessness, poor health and lower rates of education and employment.[1098]

This means that for the NDIS, the cost and impact of housing initiatives need to be evaluated and resourced in light of the significant benefits it brings.

While fundamental, housing is only one part of the equation for people with disability. For many participants, support with activities of daily living — living supports — are just as essential.

The United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) explicitly recognises the importance of housing and living supports.[1099] Article 19 commits State Parties to:

> *"Recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*
>
> *a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
>
> *b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs." – Article 19, UNCRPD[1100]

The CRPD Committee emphasises the importance of the right to live independently and be included in the community for people with disability and the ability to exercise choice and control over their lives.[1101] Article 28 of the UNCRPD also recognises the right of people with disability "to an adequate standard of living for themselves and their families, including adequate food, clothing and housing".[1102] This includes ensuring people with disability can access public housing programmes.[1103] The right to an adequate standard of living, including adequate housing, is also recognised in other international instruments to which Australia is a party.[1104]

Australia's Disability Strategy (2021–2031) (ADS) is one of the vehicles for Australia to realise its obligations as a signatory to the UNCRPD. It includes a commitment to improve housing for people with disability. "Inclusive Homes and Communities" is one of the seven key outcomes areas of the ADS. Policy priorities within this are focused on increasing the availability of affordable housing for people with disability, and ensuring that housing is accessible and people with disability have choice and control about where they live, who they live with, and who comes into their home.[1105]

Throughout this Review it has become clear that there is no one clear definition in the sector for many commonly used terms. To avoid confusion, we have defined how we use certain terms (see Box 41).

Box 41: Definitions of key terms used in this chapter

Housing and living: We use the term 'housing and living', rather than 'home and living', to directly recognise that there are two distinct but interrelated components to the supports of interest to this Review — housing supports (i.e. accommodation and the built environment) and living supports (i.e. support to assist participants with activities of daily living). There are complex interactions between housing and living supports. When working together well, these housing and living supports should create a sense of home for people with disability.

Ageing Specialist Disability Accommodation (SDA): Refers to SDA dwellings with a design category of Basic and all Legacy stock. The Basic design category applies to SDA dwellings that were built before 1 April 2016 (existing SDA). These SDA dwelling were built "without specialist design features but with a location or other features that cater for the needs of people with disability and assist with the delivery of support services".[1106] Legacy stock refers to dwellings that are designed to house six or more long-term residents.[1107]

Group home: Refers to homes where multiple people with disability, often five or more, live together under a single roof. They usually have a separate room for a support worker to provide onsite overnight assistance. Apart from staff, only people with disability reside in the dwelling. Each person has their own bedroom, while common areas, like a kitchen, bathroom or dining room, are shared with all the people living in the home. Group homes are generally provider-led, where the rhythm of everyday life is dictated by staff and service providers and

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residents have little or no say over whom they live with. By comparison, a 'share house' has many of the same features, including multiple people living together under a single roof, but has several critical differences.

Share house: Similar to a group home in that multiple people with disability live together, sharing accommodation and living supports, but with fewer residents (generally no more than three). Share houses are also distinguished by being resident-led, where people have chosen who they are living with and there are mechanisms for shared decision-making over who provides their supports and how they live their lives. Those living in share houses may have been friends before choosing to live together.

Mainstream housing: This includes home ownership, private rental market, affordable rental housing, and social housing (public and community housing).

Non-SDA supported accommodation: Housing that is not SDA but is generally only accessed by people with disability, such as Supported Independent Living (SIL) homes and Supported Residential Services (SRSs).

Shared supports: Refers to shared living supports. The term is agnostic to the setting in which supports are delivered. Supports can be shared across a household living together under one roof, but they can also be shared amongst a tenant group that have their own apartments in a single development or separate but co-located homes embedded within the community.

Transitioned participants: Refers to participants who were accessing defined Commonwealth, state or territory specialist disability support programs in operation prior to the NDIS, and entered the scheme through bilateral agreements between the Commonwealth and individual states and territories.

24/7 living supports: Refers to participants who require at least 8-hours of active support and/or supervision with activities of daily living and some level of support for the remaining hours of the day while at home, including overnight. For some participants, 24/7 support may entail active support for every minute of every day, however, this is only in specified circumstances.

2.2. The scheme currently funds a range of housing and living supports

The scheme currently funds a range of housing and living supports (see Box 42). These supports comprise a significant share of total scheme payments — both overall and relative to the proportion of participants accessing them. At 30 June 2023, 1 in 20 participants had SIL funding in their plan (5 per cent). In the year to 30 June 2023, payments to SIL participants for the support category Assistance with Daily Life were $8.8 billion, representing a quarter (25 per cent) of total scheme payments.[1108]

NDIS housing and living supports are designed to work together, but this does not mean that participants eligible for one type of support automatically receive the other. For example, not all participants eligible for SIL also receive SDA. Around 60 per cent of participants funded for SIL are also funded for SDA – this share has remained steady for the last few years.[1109] Most participants funded for SDA (80 per cent), however, also receive SIL funding.[1110] Additionally, some supports are mutually exclusive – for example, participants living in an SDA dwelling cannot receive home modifications funding.

<div style="background:#123;padding:1em;">

Box 42: What housing and living supports are funded by the NDIS?

<u>Housing supports</u>

Specialist Disability Accommodation (SDA)

SDA is housing with specialised design features available to participants with "extreme functional impairment" and/or with "very high support needs".[1111] Eligibility for SDA is set out in the *NDIS (Specialist Disability Accommodation) Rules 2021* (SDA Rules).[1112]

- 23,092 participants had SDA funding in their plan at 30 June 2023 (3.8 per cent of participants). However, only 13,971 appear to be living in SDA.[1113] There are also 1,300 participants without SDA funding in their plan who have an address-match to living in an SDA dwelling.[1114]
- $230 million in SDA payments were made in 2022-23 (0.7 per cent of scheme payments).[1115]

Home Modifications

Home modifications are adaptions to a participant's home. They can be minor, such as widening a doorway, or more complex, such as remodelling a bathroom to ensure accessibility.

- 7,259 participants claimed a payment for home modifications in 2022-23 (1.2 per cent of participants).[1116]
- $119 million in home modifications payments were made in 2022-23 (0.3 per cent of scheme payments).[1117]

Assistive Technology

Assistive technology includes equipment or devices that help participants carry out everyday activities. The assistive technology support category covers items that are not exclusively related to the home, such as a powered wheelchair or vehicle modifications. It also includes a range of equipment, technology and devices that relate exclusively to a home setting, which we refer to as home-related assistive technology. This includes, for example, remotely controlled systems to operate curtains, lights and doors or alert systems for detecting seizures or unexpected movements.

</div>

- 21,560 participants claimed a payment for home-related assistive technology in 2022-23 (3.5 per cent of participants).[1118]
- $115 million in home-related assistive technology payments were made in 2022-23 (0.3 per cent of scheme payments).[1119]

Medium Term Accommodation (MTA)

MTA is a time-limited support, typically up to 90 days, to pay for the costs of temporary accommodation (excluding support costs) if permanent housing and living supports are not yet ready. For example, it can apply while waiting to enter an approved SDA place or while complex home modifications are completed.

- 2,619 participants claimed a payment for MTA in 2022-23 (0.4 per cent of participants).[1120]
- $23 million in MTA payments were made in 2022-23 (0.07 per cent of scheme payments).[1121]

Living supports

The scheme funds a range of living supports, which are generally funded under the support category Assistance with Daily Life (ADL). This covers a range of supports, including assistance with self-care activities and assistance with household tasks, such as gardening or cleaning. It also includes community nursing supports and short-term accommodation and assistance. Many participants may only require these supports on a drop-in or ad-hoc basis. However, some participants need more intensive living supports, up to 24-hours a day, 7-days a week. Within the ADL support category these more intensive living supports are known as Supported Independent Living (SIL) and Individualised Living Options (ILO).

Supported Independent Living (SIL)

SIL is a type of support for participants with a higher level of support need – those who require 8 or more hours of active support and/or supervision per day to complete daily activities, as well as some level of support for the remaining hours of the day, i.e. 24/7 support. Generally, only participants over the age of 18 are eligible for SIL and support is often, although not always, shared. Importantly, SIL does not prescribe the housing setting in which supports are delivered.

- 31,509 participants had SIL funding in their plan at 30 June 2023 (5.2 per cent of participants).[1122]
- $8,837 million in SIL payments were made in 2022-23 (25.2 per cent of scheme payments).[1123]

Individualised Living Options (ILO)

ILO is a relatively new support category introduced in July 2020, with limited uptake to date. It is intended for participants who require at least 6 hours per day of disability related

support in the home, but not 24/7 rostered supports. It covers both host and share house-type arrangements. ILO is funded in two stages. The first, ILO – Exploration and Design, is funding to assist a participant to design their supports. The second stage, ILO – Support Model, is funding to implement and maintain supports. Not all participants who are funded for the first stage progress to the second.

ILO – Exploration and Design

- 1,344 participants claimed a payment for ILO – Exploration and Design in 2022-23 (0.2 per cent of participants).[1124]
- $3 million in ILO – Exploration and Design payments were made in 2022-23 (0.01 per cent of scheme payments).[1125]

ILO – Support Model

- 747 participants claimed a payment for ILO – Support Model in 2022-23 (0.1 per cent of participants).[1126]
- $90 million in ILO – Support Model payments were made in 2022-23 (0.3 per cent of scheme payments).[1127]

While 31,509 participants are identified as having SIL funding in their plan at 30 June 2023, there are also a significant number of participants who, while not identified as having SIL funding, received ADL funding equivalent to a SIL-like package.

Considered together, there has been significant growth in the number of participants accessing 24/7 living supports in recent years. In the 12 months to 30 June 2023, the number of participants with plans including committed SIL supports or annualised ADL budgets equivalent to SIL supports at a 1:3 support ratio (or higher) grew by 23.5 per cent to reach 40,867 (Figure 78). This growth is significantly higher than overall scheme population growth, which grew from 534,655 participants at 30 June 2022 to 610,502 participants at 30 June 2023 (14.2 per cent).[1128]

Figure 78: Number of participants funded for 24/7 living supports[1129]
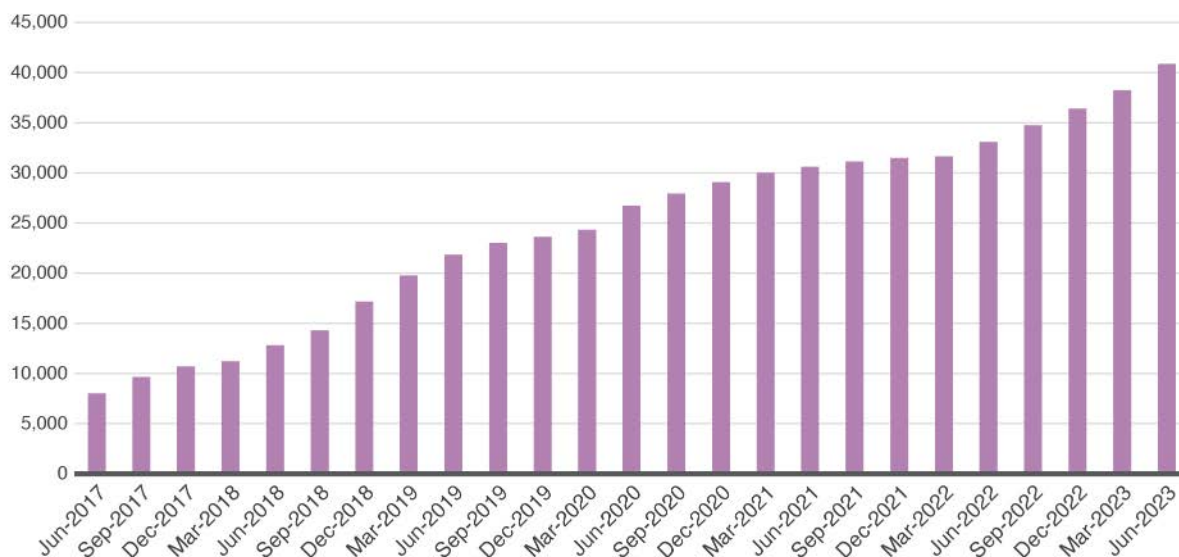
There also appears to be a substantial level of unmet need for housing and living supports.[1130] This partly stems from the number of participants living with ageing carers who deliver a lot of informal support. We analysed 2021 Census data, and found there were approximately 17,000 people aged under 50 who needed assistance with core activities, did not currently receive SIL support, and lived with a household member that provided unpaid care who is aged over 65. In the absence of the older household member who provides care, these people may require additional SIL assistance in the future. As of 1 January 2023, 44 per cent of these people were not on the NDIS, while the remainder (56 per cent) had an NDIS plan but were not receiving SIL support.[1131] It also stems from those who transitioned from previous disability services systems but have not had a proper reassessment of their eligibility for more contemporary SDA and corresponding SIL needs (see Box 44).

Ensuring housing and living supports are fit-for-purpose is therefore critical to meeting both the needs of participants and overall scheme sustainability.

Box 43: A note on data

This chapter draws extensively on scheme administrative data collected and held by the National Disability Insurance Agency (NDIA). We undertook our own analysis of the administrative data, and this analysis was then validated by the NDIA.

Estimating shared support ratios using budget sizes

The NDIA does not hold structured data on SIL funding decisions relating to a participant's shared support ratio. To create a participant's individual SIL budget the NDIA makes a

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number of decisions relating to their needs and inputs these into an internal tool it calls a 'home and living calculator.' These inputs include:

- Ratio of shared support (no sharing, sharing with 1, 2, 3 or more others)
- Support intensity (standard or high needs)
- Overnight support needs (active or passive, i.e. a sleepover support)
- Individual direct support needs beyond the baseline shared support ratio for some hours of the day or week (e.g. a participant may have a baseline support ratio of 1:3 but has specific 1:1 or higher support needs for particular times of the day or for particular activities).

The home and living calculator is linked to relevant items in the NDIS Support Catalogue, including remoteness loadings, to produce an annual SIL budget (Figure 79). Coupled with poor data on the living arrangements of participants, we have relied on these budget outputs as a proxy to estimate shared support ratios.

Participants funded for 24/7 supports

The NDIA uses a data flag called the "SIL indicator" to identify participants funded for SIL supports. In its public reporting, only participants with this SIL indicator are counted as SIL participants. However, there are a substantial number of participants who are not flagged with the SIL indicator but have an annualised ADL budget equivalent to SIL supports funded at a ratio of 1:3 or higher.

In some sections of this chapter, where indicated, we have elected to combine participants with the SIL indicator as well as those with annualised ADL budgets equivalent to a 1:3 support ratio or higher as representative of participants receiving '24/7 living supports'.

Figure 79: Annual SIL budgets from the NDIA's internal home and living calculator approximating support ratio and overnight support needs (2021-22 standard intensity non-remote prices)[1132]
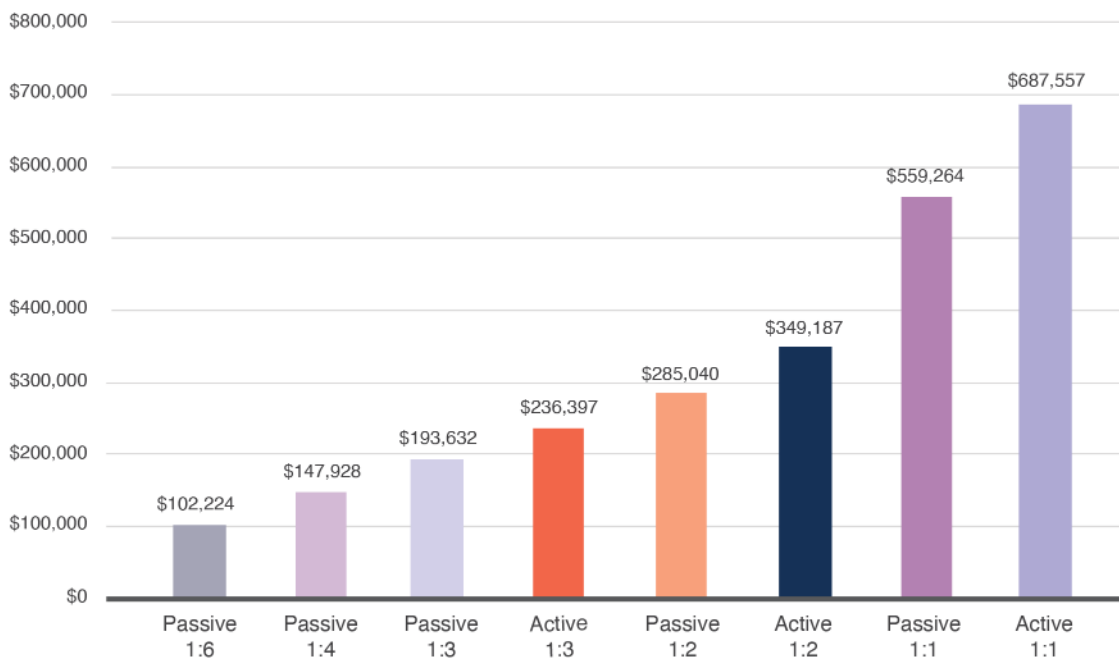
2.3. Where do NDIS participants live?

Data on the living arrangements of participants is poor. Although the NDIA collects this information from participants through the Short Form Outcomes Framework survey completed as part of the planning process, there are significant gaps in the data. At 30 September 2022:

- Over half of all NDIS participants (55 per cent) were missing information on who they lived with and almost the same proportion (56 per cent) had their living context (i.e. dwelling type) recorded as 'other'.
- For participants flagged as having SIL funding, 22 per cent were missing data on who they lived with and just over a quarter (26 per cent) had their living context recorded as 'other'.
- Participants with SDA funding in their plan were also missing data on who they lived with (21 per cent missing) and 26 per cent had a living context of 'other'.[1133]

Given these limitations, we have drawn on a range of data that examines the housing and living arrangements of people with disability more broadly.

Most NDIS participants and people with disability access the same range of living arrangements as the rest of the population but in markedly different ways (Figure 80). An Australian Housing and Urban Research Institute (AHURI) study from 2015 showed that people with disability have different 'housing careers'. They are more likely to move out of the parental home later in life than people without disability due to the absence of appropriate and affordable alternatives.[1134]

Compared to other Australians, people with disability under the age of 65 are less likely to own their home and are over-represented in housing assistance programs and in the unemployed and homeless populations.[1135]

As at June 2022, the Australian Institute of Health and Welfare (AIHW) reported that more than one third (36 per cent or 145,300) of households in the three main social housing programs (public housing, community housing, and state owned and managed Indigenous housing) included a person with a disability.[1136] It also found that 17 per cent of non-dependent people with disability who rent do so from a state or territory housing authority, compared to 3 per cent of those without disability.[1137] For 2019-20, 9 per cent of those accessing specialist homelessness services (whose disability status was known) were people with disability, of which 30 per cent had a severe or profound disability.

Living arrangements also vary considerably depending on a person's type of disability, and those with intellectual disability are particularly disadvantaged. Those with intellectual disability aged between 15 and 64 are most likely to be living with a parent/primary carer as a non-dependent child (39 per cent). This is compared to 12 per cent of people with sensory disability and 10 per cent of people with physical disability.[1138] Less than a quarter (22 per cent) own their own home, compared to 53 per cent of people with physical or sensory disability.[1139] Irrespective of disability type, people with severe or profound disability experience poorer housing outcomes.[1140]

Some housing arrangements are specific to people with disability and/or NDIS participants. SDA, MTA and ILO are all exclusively available to participants funded for this type of support by the scheme. People with disability also live in non-SDA supported accommodation, which is not funded by the Scheme, and which can include Supported Residential Services (SRS) and 'SIL homes'. There are many problems with these arrangements (see section 2.3.1). At 31 December 2022, there were also 2,423 people with disability aged under 65 years estimated to be living in residential aged care, with 49 aged under 45 years.[1141]

Figure 80: The housing spectrum for NDIS participants
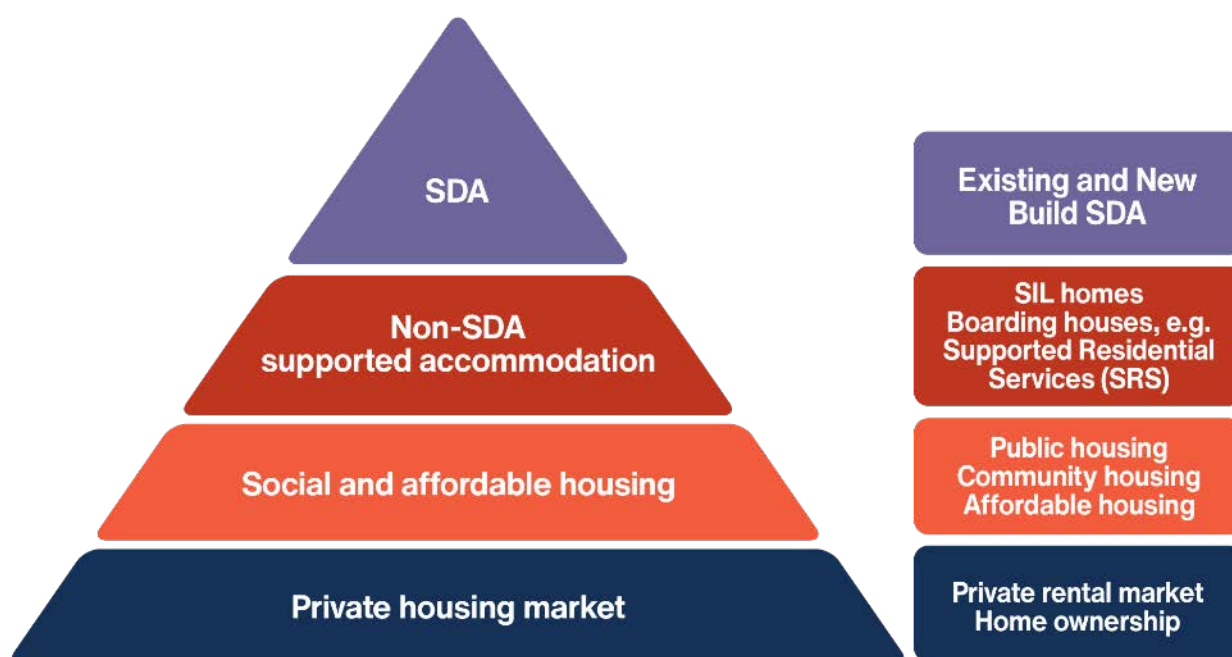
2.3.1. Closed system settings and the emergence of "SIL homes"

Closed system settings refer to environments where a single provider delivers both accommodation and living support to the same participant. Despite closed systems being against the UNCRPD, many people with disability have continued to live in closed system settings since the transition from previous disability systems to the NDIS.[1142]

In closed settings, providers can restrict and control a participant's access to other support services as the provision of accommodation is conditional on their use of, and payment for, the supports provided.[1143] SDA can be a closed system. NDIS data as at 31 December 2020 showed there were 2,388 participants receiving SIL and SDA supports from the same provider.[1144]

In response to the Joint Standing Committee on the NDIS report into SIL, the NDIA stated that, over time, it will require that SIL and SDA be provided by separate entities, to reduce the number of participants in closed settings, improve outcomes and reduce the number of conflicts of interest.[1145] However, it asserted that at the current stage of SDA market development, there are not enough SIL and SDA providers to introduce such a requirement without affecting the availability of supply.

A submission from the SDA Alliance to the NDIS Quality and Safeguards Commission's (NDIS Commission) Own Motion Inquiry on aspects of supported accommodation noted that members and other stakeholders have described to the SDA Alliance many examples of:

- participants having their choice and control unnecessarily constrained by single SIL/SDA provider entities
- inappropriate or very poorly located, designed and built housing provided by single SIL/SDA provider entities

- very poor property management and tenancy management provided by single SIL/SDA provider entities
- participants that have experienced violence, abuse and/or neglect within housing provided by single SIL/SDA provider entities.[1146]

Concerns with closed system settings and conflicts of interest were raised with the Review by many participants and advocacy groups.[1147]

> *"One advocate referred the problem of providers having "whole of life" control (providing their accommodation and supports) as "service capture". This came up many times in discussions as highly problematic, with advocates explaining the disadvantages and risk a person with disability may experience when one provider controls their whole life: "One thing that we have raised to both the Commission and to the agency has been the practice of homes where essentially it's a mini institution, and where a single agency is providing both housing and supports to a person, how that then gives rise to inherent conflict of interest and the potential for a whole host of reportable incidences. The concern is the fact that there has never been that informed choice, and this isn't meant to happen." – Disability Advocacy Network Australia[1148]*

> *"There are several risks associated with this model of service, including a reduction in safeguarding. Having a range of different service providers involved in a person's life provides additional eyes to monitor the person's safety and wellbeing. A single service provider reduces the external oversight around the supports for the NDIS participant. The client is only interacting with staff engaged by the SIL provider and may have limited means to raise concerns about the SIL provider or fear that raising concerns will put their accommodation under threat." – South Australian Public Advocate[1149]*

The dominance of SIL as the main pathway into housing and living supports, combined with tight SDA eligibility criteria and general housing affordability challenges, has seen the emergence of so-called 'SIL homes'.[1150] These are non-SDA dwellings in which the SIL provider is also the accommodation provider. This can be through direct ownership by the SIL provider, but we have heard it is more common that SIL home providers acquire a property through the private rental market via a head leasing arrangement.[1151]

These settings are poorly regulated.[1152] Unlike SDA, there are no requirements for dwellings to have specialised design features. There is also no regulatory access by, for example, community visitors. There is poor security of tenure, and no limits on participant rental contributions. As an integrated housing and living solution, participants residing in these dwellings cannot choose another SIL provider unless they also relinquish their accommodation.

We have heard that while many of the providers offering SIL homes are registered, they are under-regulated, with the NDIS Commission having limited proactive visibility over smaller providers.[1153]

"In the case of SIL Homes, there is no regulation about the dwellings themselves, the location, the density, their accessibility …. much greater regulation is required." – SDA Alliance[1154]

"In our region new unregistered providers are starting up businesses, renting private homes that are not modified or fit a persons needs and taking in SIL participants with high plan funds. What happens when the rental agreement finishes, where are these people to live in this housing crisis? These providers will cease supports and they will have nowhere to live." – Consultation, Every Australian Counts[1155]

The worst case scenario of this disregard and lack of market monitoring is evident in relation to the observed poor management, disregard for human rights and conflict of interest at play in relation to boarding houses and SRSs, acknowledged by the Disability Reform Ministerial Council (DRMC) in June 2023.[1156] This is despite evidence from the Disability Reform Council's own commissioned research in 2008 into the Effectiveness of Supported Living in Relation to Shared Accommodation, which identified that a key element of the most effective models was separation of housing and support.[1157]

Case Study 18: A mother's experience with SIL homes for her son[1158]

A mother told us about her and her son's experience with SIL, describing how it doesn't always work and is not flexible.

Previously, her son lived in a shared house with drop in support. She managed all of the rosters and carers. When SIL was recommended to her, she was reluctant at first, preferring ILO, but ended up changing to SIL to get more support.

Finding an appropriate SIL provider and house was difficult. Although there were some vacancies, she couldn't easily find them. Where there were vacancies, few had the right support ratio for her son and it was hard to match people to fill available spots. One house had been empty for two years, waiting for five participants to match. She described a lack of services that would support her son to find the right match, with nowhere for people to put up their profile and see if they could find others with similar interests who might want to live together.

"It has been a very poor experience."

They eventually found a SIL provider and a new house in a good location. After meeting with the existing resident they felt it was a good match and her son moved in. Once a third resident moved in, the mix of residents no longer worked. Her son was 32 years old and the other residents were 55 and 65. One of the residents didn't like to talk, but her son did. Those residents later moved out, leaving her son alone in a four bedroom house.

They were later advised by the provider that her son had to move out in two months as the provider needed to end the lease, even though she had specifically asked and the provider had told her they had a long lease before her son moved in. Her son doesn't have a sub-lease for the room, only a service agreement with the provider.

The SIL provider suggested a new location, but it was too far away from her son's other supports and from her home. She described how her son doesn't really have a choice or a say.

Anecdotal evidence has been provided to the Review that some SIL home providers are cross-subsidising the accommodation costs using SIL funding, to plug an affordability gap in the private rental market. But there is limited visibility of that evidence partly because, under the *National Disability Insurance Scheme Act 2013* (NDIS Act) and NDIS Rules, NDIS funds cannot be used to pay for rental costs.[1159] Anecdotally, we have heard that the level of cross subsidisation could be around 3 to 5 per cent of a participant's SIL budget.

Some have cautioned that if separation of housing and living supports occurs for all accommodation where a person might be living independently and receiving NDIS funding, a potential consequence of that could be increasing the problem of people with disability having to access open market properties, because separation would mean that cross-subsidisation of some of the housing costs with the support costs is no longer possible.[1160]

Despite these serious issues, some submissions claimed that SIL homes are addressing a housing affordability gap for many participants.[1161] The NDIS Commission's Own Motion Inquiry into aspects of supported accommodation also found that closed systems can remove some of the impediments to resolving issues for participants in a timely way, such as a SIL provider having the ability to reconfigure a house to address resident needs without waiting for the SDA provider.[1162]

These submissions and the Commission's Own Motion Inquiry tell us that the housing affordability problem is leading to undesirable living arrangements emerging for NDIS participants, in the place of better and more stable housing solutions.

Based on submissions and evidence presented, we strongly believe that the interests of participants are best served through a more structured requirement for timely and effective resolution of issues raised by participants, including more effective auditing, visitation and complaint resolution by the Commission (see Recommendation 19) rather than relying on single SIL-SDA provider entities. Given this, we recommend the structural separation of SDA and living support providers (see section 4.2.9), together with actions designed to increase housing supply (see section 4.4).

2.4. Features of housing arrangements for the future

Through the package of reforms outlined in this chapter, we envisage a future where all housing options reflect contemporary arrangements and are embedded in a human rights framework. They should be characterised by the following features (Figure 81):

- supported choice over where and with whom people live
- separation of housing and living support providers
- affordable and with security of tenure
- good dwelling design, embedded within local communities
- safe, with both natural and formal safeguards in place
- targeted use of home modifications and assistive technology that supports independence

- the right mix of quality supports.

We believe these features, combined with the right mix of quality supports, will ensure a shift away from outdated group home settings, to more contemporary settings like share houses and co-located individualised housing that enable the sharing of supports.

This would allow the scheme to deliver on its promise of quality and inclusive housing and living supports for participants while ensuring overall scheme sustainability. When working well together, these features will also combine to make a house a 'home' — the Review wants all NDIS participants to have a place they can call home.

Figure 81: Features of housing arrangements for the future

2.4.1. Supported choice over where and with whom people live

- Participants must be supported to exercise genuine choice and control over where, how and with whom they live. No one should be forced into an arrangement that is not of their choosing. This is particularly important for participants with cognitive impairment.[1163]
- Where supports are shared, they could be provided in a share-house type arrangement or in individual, but co-located, dwellings that offer individual private space but still facilitate effective sharing of supports amongst the group of residents.

2.4.2. Separation of housing and support providers

- Separation of housing and support providers can provide a range of benefits for people with disability and their families including enhanced choice, better defined accountability, clarity of roles and responsibilities, responsiveness and more specialisation.[1164] This separation of control would support participants being able to make genuine choices about who they share with.

- We have heard strong support for the separation of housing and support provision.[1165]

2.4.3.   Affordable with security of tenure

- Housing needs to be affordable, safe and sustainable for people with disability to have choice and control over their housing.[1166] The shortage of affordable housing, social housing waitlists and limited availability of accommodation in the private rental market are barriers to participants living how and where they want.[1167]
- People with disability should have the same tenancy rights as other residents. Security of tenure has been proven to contribute positively to employment outcomes and wellbeing.[1168]

2.4.4.   Good dwelling design and embedded within in the community

- A key characteristic of connected housing is the location and design of the house.[1169] Good house design contributes enormously to good quality lives. People with disability must be supported to access affordable housing that is close to transport, close to amenities, connected with ease to their place of employment and cost effective in terms of energy.
- Location should also facilitate incidental inclusion. By this we mean that the house should be connected to parks, to local shops and to local community facilities. This would ensure that a person with disability with or without support is visible, part of the community and welcomed and supported to engage with activities outside of their house, just like other Australians.
- There are many forms of housing that are dedicated to building a sense of belonging and connection. Many of these are not disability specific. Most well-known are:

  - Intentional communities — where a group of people dedicated with intent, purpose, and commitment to a mutual concern live in close proximity.[1170]

  - Cohousing — a collaborative housing model with multiple private homes typically clustered around a shared space perhaps including areas such as laundry and outdoor kitchen.[1171]

  - Build to Rent — is used to provide stability and "ownership" of rental properties without the cost of purchase.[1172] These developments typically provide shared facilities such as office and recreational space.

- House design that allows for more individualised solutions while providing for efficient sharing or living supports balances the rights of individuals to privacy, independence and choice, with the need to ensure that the scheme is financially sustainable.

2.4.5.   Formal and natural safeguards across all settings

- Formal and natural safeguards should be provided in a way that enables participants to have choice and control in how they live.[1173]
- Informal support networks are an important natural safeguard for people with disability.[1174] Informal or natural supports such as family, friends and connections to neighbours enriches lives and, over time, can build opportunities for increased independence in activities. Informal supports can assist participants to build capacity, which can increase their housing and living

options, including having more choice and control over who they live with.[1175] They can also monitor the provision of services and identify issues including abuse and neglect.

2.4.6. Targeted use of home modifications and assistive technology to support independence

- Technology has the potential to support people with disability to establish social connections and interact with communities.[1176]
- Home modifications and assistive technology can make homes safer and more accessible.[1177]
- They can also reduce the need for other supports over time through increased independence.[1178]

> *"Assistive technology should not be seen as an expense, it's an investment. Can be the difference between doing a task or needing a support worker or family member to help." – Participant*[1179]

2.4.7. The right mix of quality supports

- Supports should enhance quality of life and optimise opportunities for independence and capacity building.
- The right mix of quality supports will provide participants with greater housing and living options and be sustainable.[1180]

3. Housing and living supports that are fair, consistent, sustainable and promote choice

- Housing and living supports are currently allocated in a way that is inconsistent, inequitable, and unsustainable. Participants with similar levels of function and circumstance do not always receive similar levels of funding, and they do not have access to the information, advice and support they need to make genuine informed choices on where, how and with whom they live.
- A new clear, consistent and transparent process for allocating housing and living support budgets is needed, complemented by Housing and Living Navigators to assist participants to explore their options and implement their budgets.

Recommendation 8: Fund housing and living supports that are fair and consistent, and support participants to exercise genuine choice and control over their living arrangement

📑 Legislative change required

- 📑 Action 8.1: The National Disability Insurance Agency should change the budget setting process to ensure that housing and living budgets are consistent and sustainable.
- Action 8.2: As part of the local navigation function (see Action 4.1) the National Disability Insurance Agency should commission Housing and Living Navigators to provide advice on participants' housing and living options.

- Action 8.3: The National Disability Insurance Agency should design, fund and implement a process for participants to try new living arrangements at key life stages, before they commit to them.
- Action 8.4: The National Disability Insurance Agency should commission a shared support facilitation function to empower participants sharing supports to exercise joint decision-making.

3.1. Funding for housing and living is not always allocated fairly and consistently

There is a lack of clarity and consistency in how eligibility and budget-setting decisions for housing and living supports are made, leading to inequitable outcomes for participants. While the broader issue of opaque and inconsistent decision-making is discussed elsewhere in this report (see Chapter 2), from a housing and living perspective, these issues are magnified by the importance of these supports to participants and their significance to overall scheme sustainability. A new system for allocating housing and living supports is therefore needed.

3.1.1. Participants with similar levels of need do not always get similar levels of funding

Participants with higher and more complex needs should receive a greater share of funded support. There are, however, currently significant disparities between levels of need and allocated funding amounts — participants with similar levels of function do not always receive similar levels of funding.

This pattern is most stark for participants with Supported Independent Living (SIL) funding, where average annualised plan budgets do not correlate with reported level of function (Figure 82). In contrast, average plan budgets for all other participants more closely align with level of function (Figure 83).

Figure 82: Average annualised committed supports by reported level of function at 30 June 2023 (all NDIS funded supports for participants with SIL funding)[1181]

Reported level of function
(1 is the highest level of function and 15 is the lowest level of function)
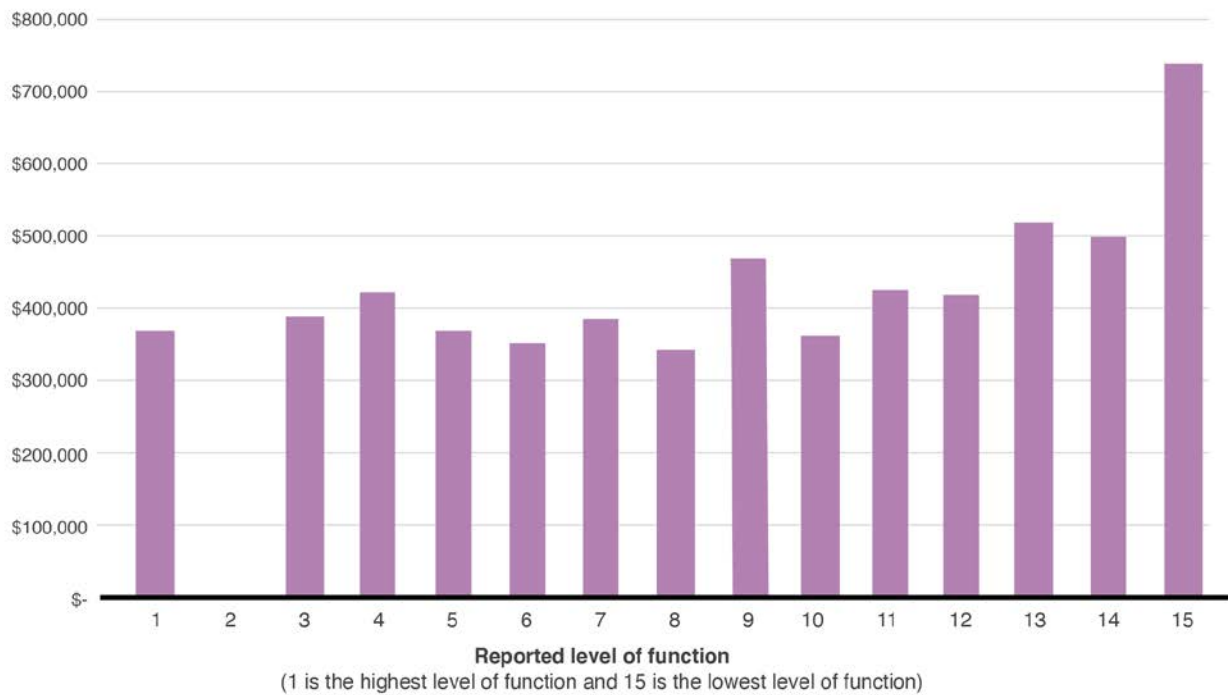
Figure 83: Average annualised committed supports by reported level of function at 30 June 2023 (all NDIS funded supports for participants without SIL funding)[1182]

Reported level of function
(1 is the highest level of function and 15 is the lowest level of function)
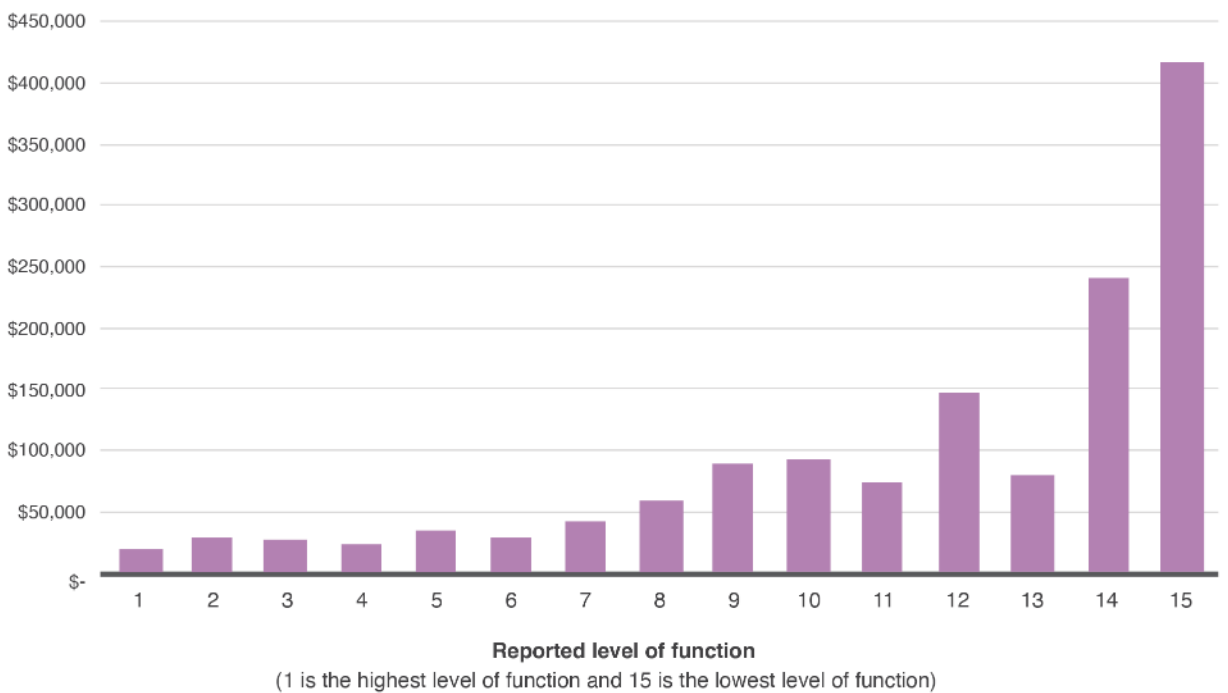
This disparity might be partly explained by the fact that a higher proportion of people with SIL were transitioned from previous disability services systems without a proper assessment of their needs (see Box 44). It may also be explained by the fact that the National Disability Insurance Agency (NDIA) has relied on budget setting approaches which are based on functional assessments, rather than supports needs, when there is not always a direct relationship between functional impairment and support needs. It is also possible that level of function is not accurately recorded.

There is also significant variation in support budgets for participants funded for 24/7 living supports depending on their primary disability type (Figure 84). While some variation is to be expected, the data indicates that, at 30 June 2023, of participants funded for 24/7 living supports, those with a primary disability type of intellectual disability (including Down syndrome) were most likely to have annualised Assistance with Daily Life (ADL) support budgets indicating they shared supports with more than 2 or more others. This may also reflect historic arrangements as most people living in 24/7 arrangements before the NDIS was introduced had an intellectual disability.

Figure 84: Participants funded for 24/7 living supports at 30 June 2023 by primary disability type and implied support ratio[1183]
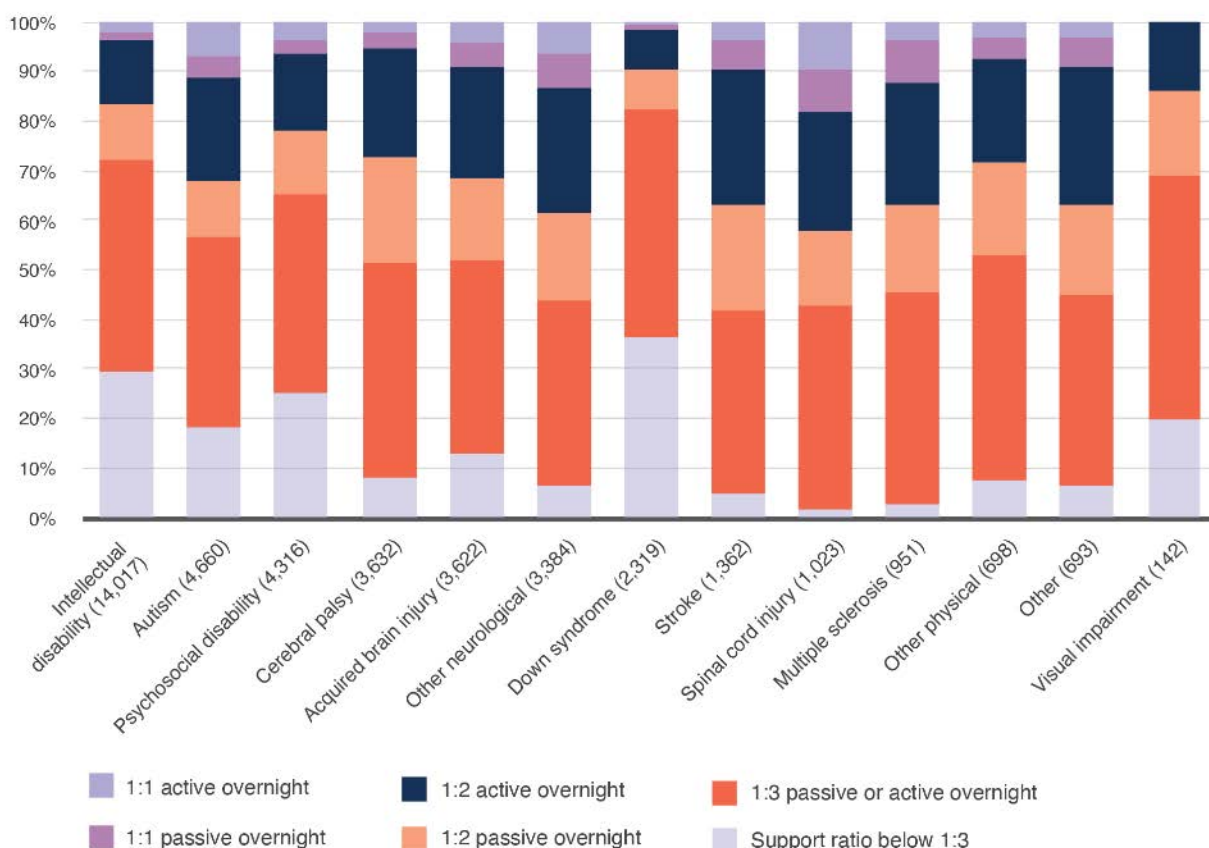
Inconsistencies extend to the allocation of Specialist Disability Accommodation (SDA) funding. Many submissions — including from carers, providers and housing and homelessness advocacy organisations — reported that SDA decisions were often not aligned with previous decisions for

participants with similar functional capacity and support needs.[1184] An April 2022 report from the Public Interest Advocacy Centre and the Housing Hub raised these same concerns.[1185]

To verify these concerns, we sought data from the NDIA regarding SDA applications, decisions, and internal and Administrative Appeals Tribunal (AAT) reviews. The NDIA was able to confirm that in 2022-23, 10.8 per cent of all planning-related AAT applications had SDA in dispute.[1186] Given only 3.8 per cent of participants had SDA in their plan at 30 June 2023, the disproportionate share of SDA-related AAT disputes suggests inconsistencies in decision-making.

> ### Case Study 19: A parent's experience of inconsistent decision-making[1187]
>
> *"My friend and I submitted our applications for SDA and SIL supports for our boys in September both have very similar needs. We worked on this together, had the same support coordinator, submitted them on the same day. We included proof that our boys have spent their entire lives together in the form of a pictorial history. My son was approved for both SDA and SIL supports and mention of pieces of information in the reports were included in the reasons why decision was made. A week or so later my friend received a rejection for SIL, SDA and in fact supports were reduced. There were also massive errors in the plan. Remembering this young man is the child of a 73 year old woman who needs to make plans for her son's future. My friend was totally devastated. There was no mention of any of the information provided in the reports and in fact it implied that no evidence had been supplied. I can assure you this was not the case. This is still not resolved some nine months later. This has of course delayed both our plans as funding precludes my son living on his own."*

Inequities also apply in the case of participants transitioned into the scheme from previous government funded systems (see Box 44).

> Box 44: Transitioned participants have been particularly disadvantaged in their funding allocations
>
> Participants transitioned through the bilateral agreements from defined state, territory and Commonwealth disability support programs have not been afforded the same opportunities to access more contemporary housing and living arrangements.
>
> Many have had limited change in their living situation since transitioning into the scheme. This has largely been driven by the sheer volume of participants that entered under the bilateral agreements during the transition to full scheme. During this period, the NDIA had a greater focus on meeting access targets, rather than undertaking a comprehensive assessment of need. As such, many pre-scheme support arrangements endure to this day. In its Own Motion Inquiry into Aspects of Supported Accommodation the NDIS Quality and Safeguards Commission (NDIS Commission) noted:
>
> > *"There has been limited engagement with those people who have transitioned to the NDIS from state and territory funding arrangements about options for more contemporary living arrangements within the NDIS, should people wish to explore*

> *these. This is mainly left to their current providers to facilitate on an individual or house by house basis, and almost always limited to the options that the current providers might have available." – NDIS Commission[1188]*

At 30 June 2023, transitioned participants represented almost 4 in 5 (31,727) of those receiving 24/7 living supports.[1189] Compared to those who have only ever known the NDIS, transitioned participants are almost twice as likely to have a plan budget size that indicates sharing with more than 2 others (22 per cent compared 13 per cent).[1190]

Inequity extends to those living in SDA. At 30 June 2023, 11,086 participants funded for 24/7 living supports could be exactly matched to living in an SDA dwelling.[1191] For participants living in SDA, indicative analysis suggests that more than 2 in 5 (44 per cent) transitioned participants lived in ageing SDA, compared with less than 1 in 5 (17 per cent) new participants.[1192]

The disability profile of transitioned participants accessing 24/7 living supports is also distinctly different. Nearly half (48 per cent) have a primary disability type of intellectual disability, including Down syndrome, compared to 11 per cent of non-transitioned participants (Figure 85). Transitioned participants are also more likely to have a lower level of function, with 75 per cent having a low level of function compared to 65 per cent for non-transitioned participants.[1193]

Figure 15: Proportion of participants funded for 24/7 living supports at 30 June 2023 by primary disability type and entry pathway to the scheme[1194]
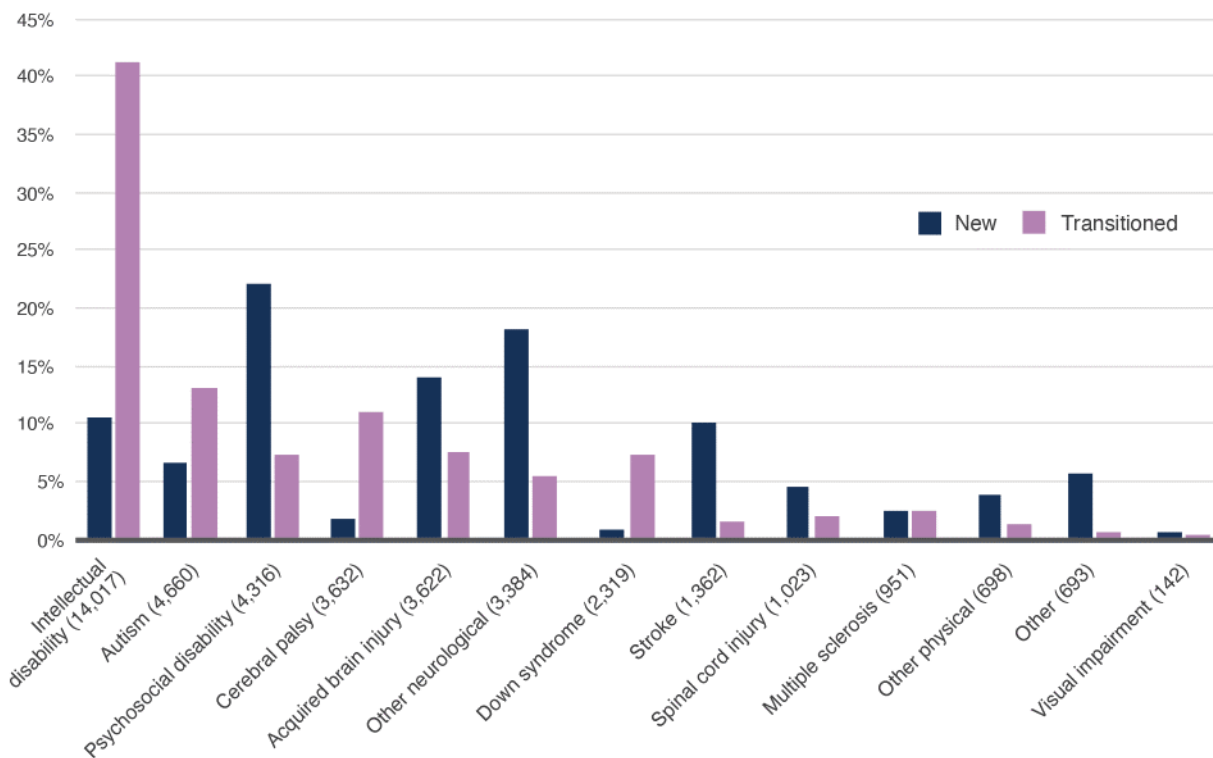
3.1.2. Living alone with no sharing of supports can be a key driver of scheme costs

Participants who need 24/7 living supports are usually funded to share support. This could be in an outdated congregate setting, such as a large group home, or a more contemporary setting, like a share house. It is more expensive to live alone and not share living supports, unless a participant has access to informal supports that replace paid formal supports (Figure 86). In some cases, participants live in individual dwellings that are co-located and share only overnight supports. This too is an expensive option if there is no sharing of supports during the day.

Figure 86: Simplified support cost matrix for participants requiring 24/7 living support, based on level of informal supports and level of sharing of formal supports

Budget outputs from the NDIA's internal home and living calculator show the most significant cost increase occurs when a participant moves from sharing supports with at least one other to no sharing at all (Figure 79). In 2021-22, a participant funded for 24/7 living supports sharing with two others (1:3 support ratio) with passive overnight support required an annual living support budget

of $193,632. By comparison, a participant who did not share 24/7 living supports (1:1 support ratio) required an annual budget of at least $559,264 – a 189 per cent increase.

Using these budget outputs and accounting for annual price limit changes, our analysis of NDIA data shows that the proportion of participants funded for 24/7 living supports equivalent to 1:1 support has been steady over the last three years, averaging 7.6 per cent over the period 30 June 2020 to 30 June 2023 (Figure 87). However, the absolute number is increasing – growing from 2,005 to 2,882 participants over the same period. This is one factor contributing to increasing scheme costs.

Figure 87: The share of participants funded for 24/7 living supports by implied support ratio[1195]
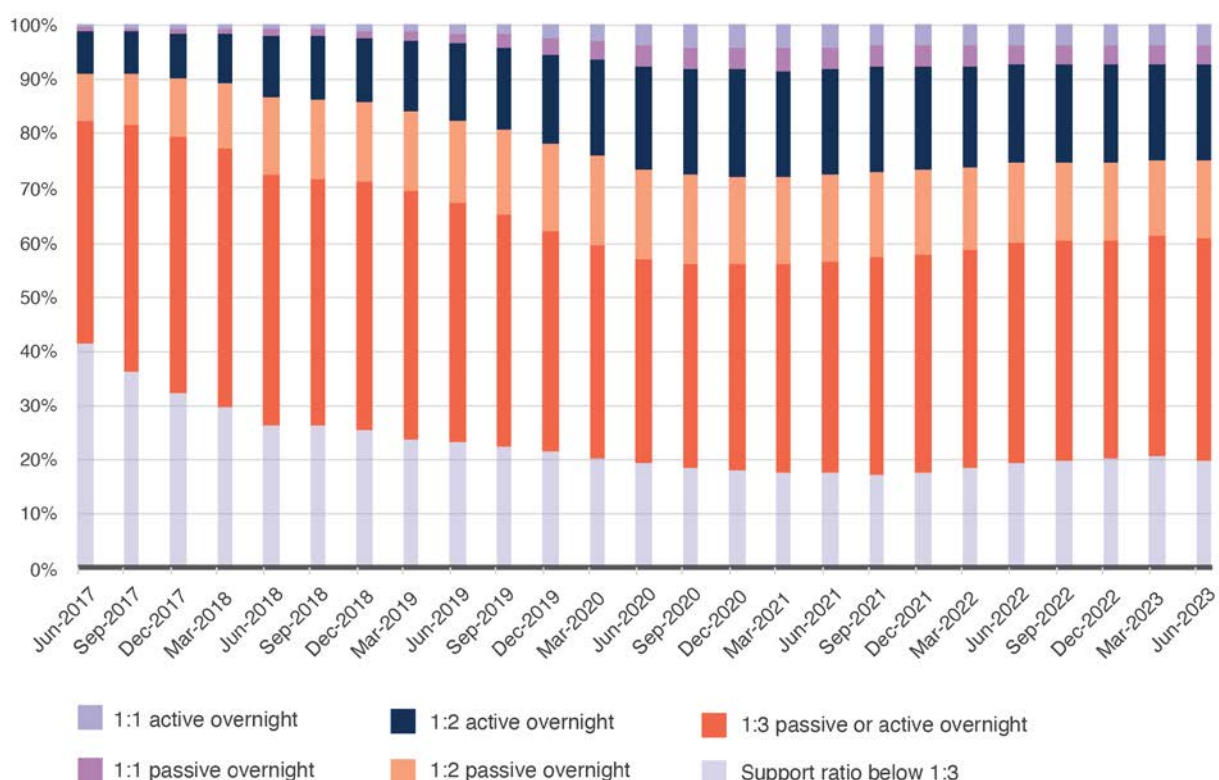
Additionally, there are growing demands from some participants to live alone:

- A recent survey of 143 participants (or their families, carers, or other informal supporters) revealed that 29 per cent were not living where or how they wanted to.[1196] Of these, 45 per cent wanted to live alone in their own home (either owned or rented), 18 per cent wanted to live in a share home (either with or without other people with disability), and 11 per cent wanted to live in a group home (operated by a service provider).[1197]
- Data provided by SDA Services, a registered service provider which supports participants to apply for SDA funding, shows that between January 2019 and January 2023 they supported 676 participants to apply for SDA, with almost 2 in 3 (64 per cent) applying for single resident SDA.[1198]

- Submissions have also conveyed that there is a strong desire amongst participants to live alone and that participants should not be pressured into living arrangements that they do not want.[1199]

In September 2021, the Office of the Scheme Actuary prepared a report which estimated if 5 per cent of SIL participants currently sharing with at least one other moved to a 1:1 support arrangement, scheme costs for 2021 would have increased by $523 million in respect of only 1,255 participants (Figure 88).[1200]

Figure 88: Indicative costs if 5 per cent of SIL participants sharing with 2+ others moved to living alone with no sharing of living supports[1201]
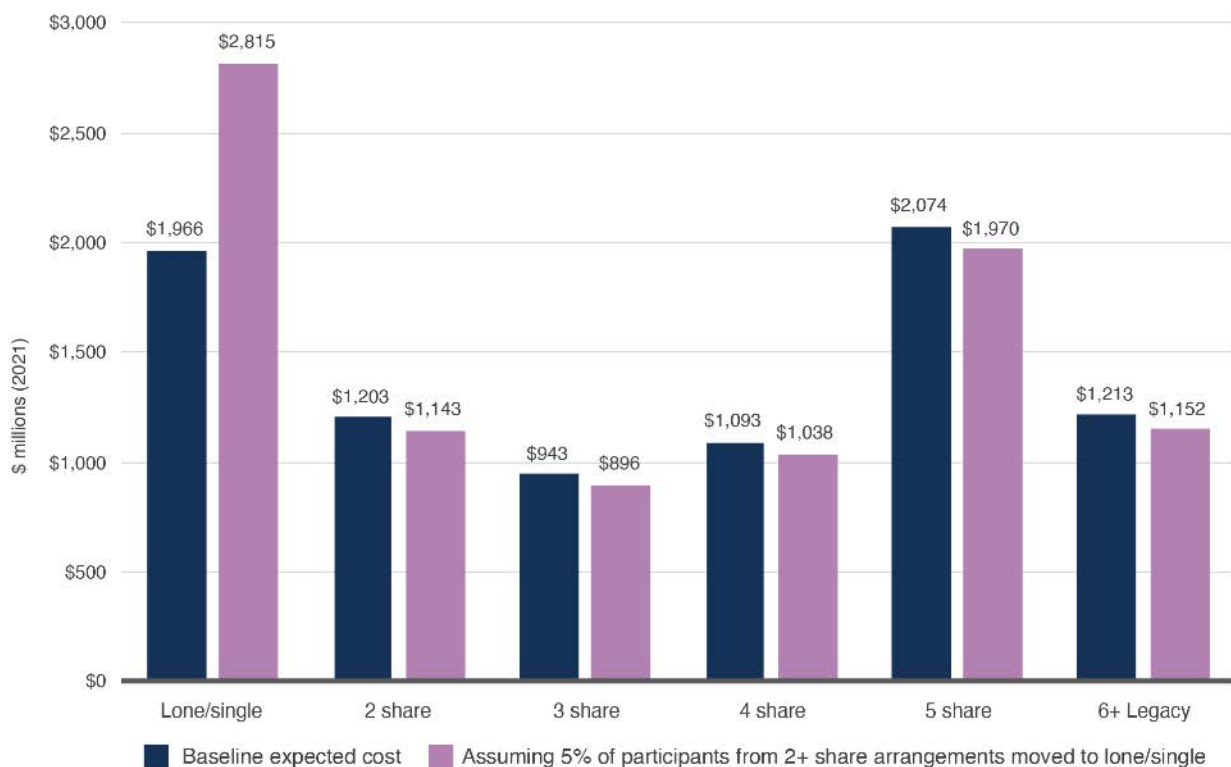
Leaving aside the potential costs, there are other problems with widespread expansion of 1:1 living supports for participants with 24/7 support needs.

- Both participants and providers report difficulty finding and keeping workers with the right skills, values and attitudes (see Chapter 4). An ageing population and growing demand for care and support services (disability, aged care and veterans' care) suggests there will be a shortfall of 285,000 care and support sector workers by 2049-50.[1202] Even with greater funding, widespread adoption of 1:1 24/7 support could not be realised due to workforce constraints.
- Living alone is not necessarily in line with community norms. In 2018, only 8.6 per cent of people aged 25 to 64 without disability lived alone, compared to 19.6 per cent of people with disability.[1203] That people with disability are more than twice as likely to live alone as the

broader community does not align with the scheme's principles of promoting inclusion, nor the concept of an ordinary life.

- Reliance on 1:1 24/7 living supports can foster dependency, increase risks of exploitation and reduce focus on capacity building and opportunities to increase social and economic participation.[1204]

As a result, we believe that it is reasonable and necessary that funding for participants requiring some degree of 24/7 living supports (whether that includes active or passive overnight support) be on the basis of those supports being shared.

In general, funding should be based on an average shared support ratio of 1:3. This will enable participants who are currently funded to share supports with three or more others to access more contemporary shared arrangements, if that is their choice. It will also support overall scheme sustainability.

However, flexibility is needed in line with a needs-based assessment process. There might be times where it is appropriate for participants with 24/7 living support needs to be funded for an average support ratio higher or lower than 1:3 due to, for example, their access to informal supports, the episodic nature of their disability (in the case of psychosocial disability) or their particular living arrangement.

For example, someone might be better off with 1:2 funding if they need more intensive supervision and/or physical assistance with daily tasks for more hours of the day, or struggle with group based activities, or have moderate to severe behavioural triggers that must be managed through a behaviour support plan. On the other hand, someone might be suited to funding for a 1:4 support ratio if they have more independence in daily tasks and/or strong communication /social skills, and strong informal support networks.

While some participants may prefer or need to live alone (see section 3.1.3), sharing supports and living alone are not mutually exclusive. Sharing supports can look like many things and does not involve necessarily living under the one roof with other people. Well-designed dwellings can facilitate privacy and autonomy, whilst still enabling the effective delivery of shared supports, both day and night — for example, amongst a tenant group that have their own apartments in a single development or separate, but co-located, homes embedded within the community. Several successful examples of this approach were highlighted (see section 4.1.2).

It is reasonable and necessary that funding for participants requiring some degree of 24/7 living supports (whether that includes active or passive overnight support) be on the basis of those supports being shared.

3.1.3. In limited circumstances, living alone with no sharing of supports may be appropriate

We received many submission calling for 1:1 or higher funding for participants in some circumstances.[1205]

"It doesn't work putting a household of people with behaviour issues in the same house. It quickly becomes very dangerous for participants and staff. People with mental health or behavioural issues either need more 1 to 1 or 2 to 1 staff, or individual housing options." – Carer[1206]

"Participants with significant trauma, intellectual disability, and behaviours of concern frequently find it difficult to live with someone else in a shared living environment." – Provider[1207]

"not capable of sharing SDA robust build accommodation with another participant due to the risk of injury and possibly death as a result of my participant's extremely challenging behaviours combined with his size, strength and his propensity to target other people with a disability." – Sunshine Specialist Supports[1208]

"The scheme needs to understand that some people need more than group supports or 1:1 support to safely participate in the community and make non-paid connections/friends. It's not hard, just accept it and fund it. I would love for my daughter to access the community more regularly as befits her age (21) and be a part of something bigger but without 2:1 she can't do so safely, so she stays home on her pc most of the day which does nothing to advance her independence goals." – Carer[1209]

While we think that it is reasonable and necessary that most participants requiring 24/7 living supports be funded on the basis of those supports being shared, we agree that for some participants in some specified circumstances, it is appropriate for the scheme to fund non-shared 24/7 living supports, or sharing of only overnight supports.[1210] This could include in cases such as:

- Participants with very complex needs who would require 1:1 (or higher) supports, irrespective of how many others they lived with.
- Where there is a risk of harm to self or others from sharing.
- Participants with families, in particular, dependent children.

Specific examples of this could include participants who have exceptional behaviours of concern (such as sexualised behaviours, violence or absconding), have behaviour support plans and actively managed restrictive practices in place, require full assistance and constant supervision in the community and/or for daily living, or pose a threat to others in group based activities unless actively supported.

Before decisions are made to fund a participant to live alone with no sharing of supports, the ability to share supports whilst residing in an individual housing setting should be explored. Relevant considerations include:

- Can the same results for a person be achieved at a lower cost (for example, by having their own space in a private apartment, within a shared environment, allowing them to share some costs)?
- What is the evidence that 1:1 support will substantially improve life stage outcomes and benefits in the long term?
- Will 1:1 funding reduce the cost of other supports over time?
- To what extent will the funding make the person more independent, and/or reduce the cost of other supports over time?

The decision of whether or not to fund a participant to live alone with no sharing of supports (or only sharing of overnight supports) should also extend to the associated SDA decision. Single resident SDA dwellings that are not conducive to sharing supports, or are only suitable to sharing supports overnight, should only be approved in specified circumstances.

Given the extent to which single living with no sharing of supports, or only sharing of overnight supports, can drive scheme costs, tighter, clearer and more consistent rules around when participants are eligible for this funding should be developed. This should be done by the NDIA together with participants, the sector and relevant professionals, and the specified circumstances under which it should be allowed should be enshrined in legislation.

While tighter and more consistent criteria for 1:1 funding will mean that the preferences for some will not be able to be met, participants funded for shared supports could still access 1:1 (or higher) supports if they have access to enough informal supports to make this work within their plan budget.

For participants living with immediate family who do not meet the criteria for 1:1 supports, guidelines on how respite care will be covered in budgets, and how the change of circumstances process will apply when there are changes to family dynamics, such as a relationship breakdown, should be developed.

3.1.4. These changes will complement the updated budget setting process for housing and living supports outlined in Chapter 2

As noted in chapter 2, we are recommending a fairer and more consistent participant pathway. Key elements of this include:

- Whole-of-person reasonable and necessary funding packages determined through a structured needs assessment process and tool(s).
- Greater flexibility in how participants can spend their reasonable and necessary funding package.
- Access to a Navigator to help people to find and coordinate the support they need and achieve what is important to them.

This section outlines how this new pathway will be applied to housing and living budgets, with a particular focus on how participants with 24/7 living support needs will be supported to explore a wide range of arrangements to find one that best meets their needs and preferences (Figure 89).

Figure 89: The new housing and living pathway for participants with 24/7 living support needs

| Pre-budget setting | **New participants** with 24/7 living support needs will, initially, follow the same pathway as all other people with disability (Recomendation 3). |
| | **Existing participants** would, at key life stages, be supported by navigators to explore alternative living arrangements and go through a change of circumstance process. |

Needs assessment and budget setting

Holistic assessment to understand needs

A comprehensive assessment of need is undertaken by a skilled Assessor. Participants will have as long as they need to ensure they are understood and will be able to view the assessment before the budget is set.

Depending on the participant's needs, circumstance and life stage the housing and living budget may include: SDA, home modifications, medium term accommodation, housing related assistive technology and/or 24/7 living supports. These supports will all be stated.

Provisional housing and living budget set

Where the holistic assessment reveals a need for 24/7 living supports, the participant receives a provisional budget based on their maximum support intensity and individual overnight support needs. Assessors and participants have clear guidance on exceptions where 1:1 living supports, with no or limited sharing, is reasonable and necessary.

Exploring and securing supports

Navigation to support participant to explore and evaluate different living arrangements

Options explored must not exceed the participant's provisional budget amount. Participants with different overnight support needs can share with each other, opening a wider range of options.

Participant chooses preferred living arrangement and provider advises actual cost

Living support provider working with navigator or shared support facilitator advises actual cost of providing services based on individual participant support needs, model chosen and, in shared arrangements, how supports will be pooled and shared across participants. The actual cost for a participant cannot exceed their provisional budget.

Housing and living budget adjusted to reflect the actual cost of the preferred arrangement

The NDIA adjusts the value of the participant's living support budget to reflect the actual costs of the arrangement.

Maintaining supports

Participant accesses supports with ongoing check-in on progress from navigator and support from shared support facilitator.

Housing and living supports will be considered holistically

There are significant interdependencies between housing and living supports. For example, the type of SDA dwelling approved can significantly impact on living support funding because of how much easier it is to share supports in that dwelling. Investment in home modifications such as ramps and rails, and home-related assistive technology such as automatic blinds and door mechanisms, can also increase a participant's independence and decrease their need for paid living supports.

> *"A participant needs housing and supports that work together to create a sustainable and secure environment. To ensure a participant's NDIS funding best meets their needs, housing and housing supports must be considered together." – Summer Foundation[1211]*

> *"We consider that what has been unintentionally lost is a focus on individual needs. This includes a fair and reliable assessment of the benefits of the SDA model of accommodation in supporting the person's life goals and life stage outcomes, and demonstrated ability to assess value for money for that person" – SDA services[1212]*

Despite this, we have heard that housing and living supports are often not considered holistically.[1213] For example, SDA decisions are often made separately to SIL decisions.[1214] There has also been limited investment in assistive technology and home modifications to-date. For the year ending 30 June 2023, payments for assistive technology, home modifications and SDA represented only 3.5 per cent of total scheme payments.[1215] This is substantially lower than the Productivity Commission's original full scheme forecasts, which estimated that in 2018-19 aids and appliances and home modifications would comprise 5.6 per cent of the gross cost of Tier 3 individual supports.[1216]

This limited investment in assistive technology and home modifications is despite their promise of creating greater independence, providing longer term stability by avoiding the need for relocation, and reducing reliance on more costly labour supports. Preliminary results of a recent study of 15 people with disability with complex support needs found that after 6-24 months of living in SDA with appropriate assistive technology, there was an average decrease of 2.4 support hours per participant per day 6-24 months following their move to the new arrangements.[1217]

We believe greater investment in these types of supports can improve participant outcomes, increase independence and support overall scheme sustainability. Central to achieving this ambition is a revised budget-setting approach that sets a reasonable and necessary funding package at a whole-of-person level (see Action 3.3). It will also be essential to remove barriers to the effective utilisation of these types of housing and living supports (see section 4).

These actions, however, cannot stand alone. Participants need support to effectively deploy their housing and living support budget (see sections 3.22 and 3.33).

Participants will have more flexibility in their housing and living budget

Currently, most participants with housing and living support needs are allocated into specific funding categories like SIL and Individualised Living Options (ILO). This is overly prescriptive and narrow and not reflective of the diverse needs and preferences of participants.[1218]

> *"Ask participants what they need and don't approach it from trying to slot them into categories that the policy has already defined" – NDIS participant, JFA Purple Orange NDIA Home and Living Consultation Report*[1219]

SIL is also poorly defined, and there is currently much confusion over what SIL actually means. SIL has existed as an NDIS support category since scheme commencement. It was designed to support participants requiring a significant amount of support throughout the day while at home, including overnight support – that is, 24/7 support.

However, there is limited clarity on whether or not SIL supports are designed to be shared. From the first 2016-17 *Price Guide* to the current 2023-24 *Pricing Arrangements and Price Limits*, SIL has consistently been described as a support that provides assistance and/or supervision with tasks for daily living in a "shared living environment".[1220] Other NDIA policy documents, however, are less clear. The NDIA's Operational Guideline for SIL states "you can get supported independent living if you live with other participants or on your own".[1221]

There is also confusion over SIL as a living support versus accommodation setting, with many submissions equating SIL to support delivered in a group home.[1222] Although SIL is a funding product that does not prescribe a delivery setting, most participants with SIL funding do live in a group home setting. At 30 June 2023, 10,647 SIL participants could be exactly matched to living in an SDA dwelling. Of these, 7,710 (72 per cent) lived in a 4 or 5-person group home or in Legacy Stock (Figure 90). The growth of non-SDA group living settings for participants with SIL funding – "SIL homes" – has reinforced this perception (see section 2.3.1).

Figure 90: Number of participants funded for SIL with an exact address match to living in an SDA dwelling at 30 June 2023[1223]
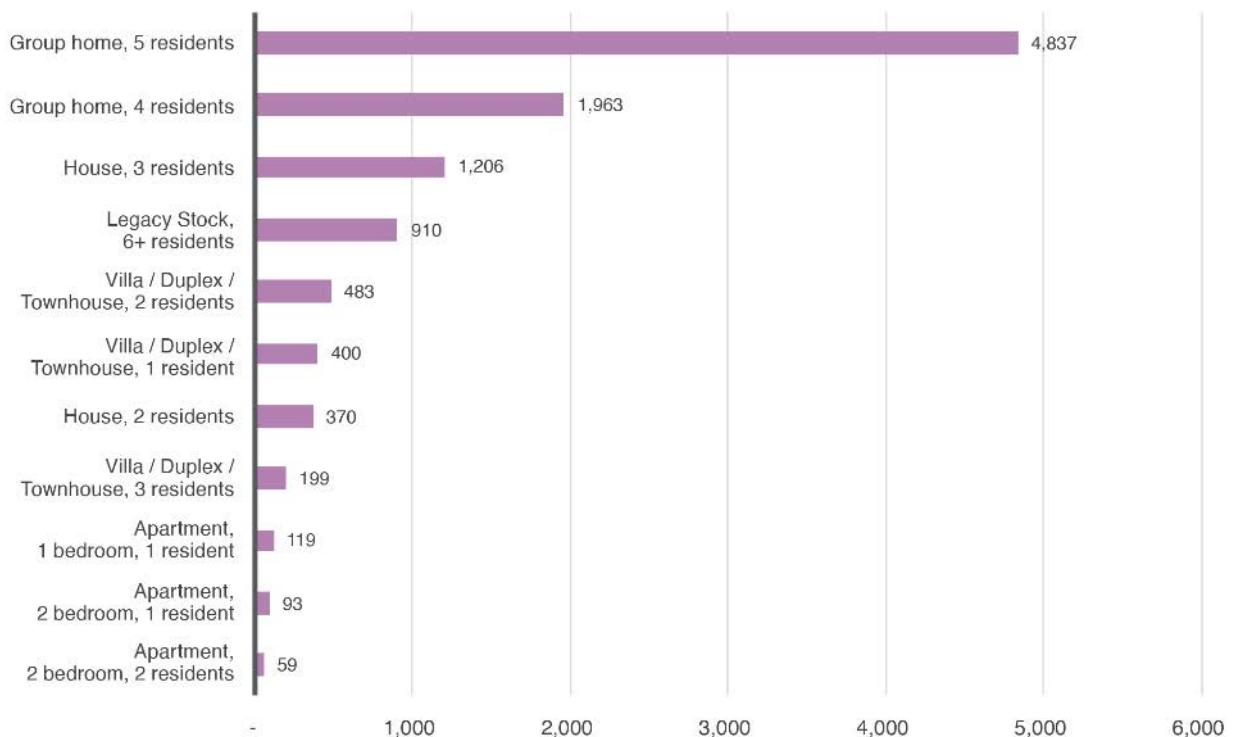
We see a need to move away from product categories, and instead describe the features of the types of supports that an individual needs. For this reason, we do not see a place for the term 'SIL' or 'ILO' in the future. We propose a move to describing supports as 'shared' versus '1:1 with no (or little) shared component', and '24/7 (passive or active overnight)' versus 'drop in'.

Under the new budget setting process, participants will be allocated a housing and living support budget that reflects an assessment of their needs, which they can deploy flexibly in accordance with their preferences, and within the constraints of their budget.

As outlined in chapter 2, the housing and living budget will be separate from the general budget, and will include any funding approved for SDA, home modifications, medium-term accommodation, housing-related assistive technology, and 24/7 living supports. A participant may use their general budget to top up their housing and living supports budget, but not vice-versa (i.e., the housing and living budget cannot be used on non-housing and living supports).

Items within the housing and living budget will be stated, which means that they cannot be used for another purpose. This includes:

• Capital funding such as SDA and high-cost home modifications and housing-related assistive technology — because these supports are intended for a specific purpose and designed to reduce the cost of other supports and should not, therefore, be used flexibly on other supports or interchangeably.

- Funding for 24/7 living supports — this will ensure providers of living supports have certainty of funding and can viably deliver supports, in line with the integrated service delivery approach outlined in section 4.1.6. Where supports are shared, it will ensure that an individual participant cannot use their shared living support budget for another purpose and, in doing so, prevent there being adequate funding to cover the group's shared living support arrangement.

Even though 24/7 living support funding will be a stated support, there will be no product categories attached to it, such as SIL or ILO. The needs assessment will determine the maximum support intensity and level of overnight support that a participant is eligible to receive, and this will create a provisional housing and living support budget. With the support of their Navigator (see section 3.2), participants will then be able to explore different living arrangements (see section 4.1) and choose one that best fits their needs, circumstances, preferences and budget.

The provisional budget should be individualised so as not to restrict a participant's choice of living arrangements to only those where everyone has the same level of overnight support needs. For example, the provisional budget of someone requiring active overnight support would assume no sharing of the active overnight component of their support so as to allow for flexibility of any match. This means that if you have active overnight support needs, these are funded at 1:1 in your provisional budget, enabling you to choose to live with others who do not have active overnight support needs.

Once a participant has decided on their preferred living arrangement, the provider would need to determine the actual cost of delivering supports. In shared living arrangements, the actual cost will need to reflect how supports, including overnight supports, will be pooled and shared. Actual costs cannot exceed any individual participant's maximum provisional budget and must comply with the price caps. There should be flexibility to adjust the actual cost (as long as it remains within the provisional budget amount) when there are changes to the composition of the group of people sharing supports (see section 4.1.6) without triggering a need for a budget reassessment.

This flexibility will need to be accompanied by enhanced quality and safeguarding arrangements to ensure that participants are protected from exploitation (see chapter 5), and enhanced decision making support (see chapter 2 and section 3.2). In shared settings, participants should also have the support of a Shared Support Facilitator (see section 3.3).

3.1.5. Action & Implementation Details

Action 8.1: The <u>National Disability Insurance Agency</u> should change the budget setting process to ensure that housing and living budgets are consistent and sustainable

The budget setting process for housing and living supports should ensure housing and living budgets are consistently based on an assessment of need and are considered at a whole of-person level (see Action 3.3).

Funding for participants requiring 24/7 living supports should typically be on the basis of those supports being shared. In general, reasonable and necessary funding should be based

on an average shared support ratio of 1:3, consistent with an assessment of need that determines the maximum support intensity and level of overnight support that a participant is eligible to receive. This should create a provisional budget amount that is the maximum participants can use in considering different living arrangements, with the support of their General Navigator (see Actions 3.3, 4.1 and 8.2).

Participants should have flexibility to choose a living arrangement. The provisional budget should be individualised and not restrict choice of living arrangements to sharing supports with other participants with the same level of overnight support needs. Once a participant has decided on their preferred living arrangement, the provider should determine the actual cost of delivering supports for the participant. In shared living arrangements, the actual cost should reflect how supports will be pooled and shared. Actual costs should not exceed any individual participant's maximum provisional budget and must comply with the price caps.

Individualised 1:1 (or higher intensity) living supports with no shared component or only sharing of onsite overnight support, and any associated single-resident Specialist Disability Accommodation (SDA) funding, should only be considered reasonable and necessary in specified circumstances. This could include, but not necessarily be limited to, where there is evidence of risk to self or others from living in a shared arrangement, participants with dependent children, and those with very complex needs. The specified circumstances criteria for 1:1 living supports and associated SDA funding should be set out in NDIS Rules.

Transition to new budget setting arrangements for 24/7 living supports should be graduated. Participants should be supported to explore shared support arrangements but should not need to move from their current home unless they choose to do so (see Action 26.2).

Implementation detail:

- The NDIA should work with participants, the sector and relevant professionals to:

  - Design, test and implement a process for determining the specified circumstances in which participants will be eligible for 1:1 24/7 living support funding (with no sharing of supports or only sharing of onsite overnight support).

  - Determine what evidence will be required for a successful application for 1:1 24/7 living support funding (with no sharing of supports or only sharing of onsite overnight support). This should include evidence on:

    o the nature and severity of risk to self or others posed by the participant sharing with others

    o whether the same results for a person could be achieved at a lower cost — for example, their own space in a private apartment, within a shared environment — allowing them to share some costs

    o how 1:1 supports will substantially improve life stage outcomes and benefits in the long term

> o to what extent the funding will reduce the cost of other supports over time.
>
> - Develop guidelines for participants living with immediate family on how respite care will be covered in budgets and how the change of circumstances process will apply when there are changes to their family dynamics.
>
> • Participants funded for shared supports could still access 1:1 (or higher) supports if they have access to enough informal supports to make this work within their plan budget, or can supplement with their own income.

3.2. Participants do not have the information and support needed to make housing and living decisions

No matter who you are, deciding on where and with whom you wish to live is a decision that takes research, advice and time. However, many participants are not supported to prepare for housing and living solutions early. When considering options, they cannot easily access the information and support that would enable them to explore and compare different housing and living solutions, both within and outside the scheme, or trial alternatives.

As a result, there is often no effective choice and control, as it is impossible to choose between alternatives outside one's experiences. This particularly affects those with cognitive disabilities or limited informal support networks. Access to independent, specialist advice on housing and living supports, and the chance trial new living arrangements before committing to them, is essential.

3.2.1. Participants are not well supported to build independence in living skills early

Families of young people with disability are not supported to help build their independent living skills. They also lack the support necessary to envisage and build strategies that enable consideration of a diversity of living arrangements for their child during their formative years.

We have heard planning conversations are often disjointed and short term, and that it is difficult to shape sequential plans for a young person to focus on investment in skills that build independence over time.[1224] There is little guidance and limited frameworks for allocating capacity building funds to assist families to identify and invest in skills that prepare young people for living outside of the family home in arrangements that mirror the diversity for the rest of the population.

> *"Both informal and formal supporters (for example, family and support workers) can facilitate building an NDIS participant's capacity to live where and how they want by providing active support." – NDIA, Having a Go report[1225]*

Budget setting and implementation processes should recognise the supports families need to optimise participants' independent capacity and envisage, explore and build options so that there is real choice when the participant is ready to transition out of home. This requires National Disability Insurance Agency (NDIA) processes to take a long-term view of building independence,

setting goals, shared and collaborative regular reviewing of progress against these goals, and adjustment of capacity building funding to respond to strengths and weaknesses as these emerge.

This would mean that planning in the early years for housing independence and choices would incorporate consideration of staged and deliberate capacity building to optimise independence in daily living skills and decision making over time including:

- self-advocacy, including speaking up about needs and preferences
- daily tasks such as safety in using the internet, communication, shopping and household tasks, cleaning and cooking
- developing routines for self-care and contribution to a household
- problem solving skills
- positive decision making skills such as appropriate clothing and safe relationships
- building confidence of parents and informal supports in risk management and safeguarding solutions.

Such an approach would not only support families and lead to more independent lives for participants, but also serve as a key financial sustainability measure. An early focus on building the capacity of participants to live more independently has the potential to reduce the need for future high-intensity and/or 24/7 living supports, especially when combined with an increase in diversity of housing and living support service models (see section 4).

To achieve this focus, it is essential that the Navigators available to the participant (see section 3.2.3), and families, are skilled and trained in capacity building strategies across life stages, and focus on building a participant's own agency.

To enable participants to have choice in their housing and living arrangements, it is essential that capacity building supports throughout their life, starting from an early age, focus on optimising skills and confidence in independent living skills. This will also reduce the need for future high intensity living supports.

3.2.2. Participants and their families need more time to explore and understand housing and living support options

To make informed decisions about where and whom they live with, participants, their families and carers need enough time to understand what their housing and living support needs are, as well as the housing and living options that are available to them.

For many people with and without disability, the need to explore different housing and living options typically occurs as a result of a change in a person's life stage or a change in a household's circumstances.[1226] This could include circumstances such as people looking to move out of the family home as they pursue education or employment, people wishing to move in with a partner and families growing or downsizing.

At such points, participants often need time to first figure out what their housing and living needs and preferences are, as well as how their lives at home might change. Participants and their families

also need time to understand the range of housing and living support options available. For many participants, this requires navigating across multiple service systems, both outside and in the scheme.

Additional time may also be needed for some participants and their families to try out different housing and living solutions to understand what does and doesn't work for them, and to build the skills and confidence needed to live comfortably in their new housing and living arrangements.[1227] This is particularly important for participants who want to live more independently (see section 3.2.1).

The length of time needed by participants to explore and establish suitable housing and living solutions will vary depending on an individual's circumstances and capacity.[1228] One study has shown that 2 to 5 years was the most chosen ideal timeframe for people with disability and their families to explore and move to a new living arrangement (Figure 91), but they expected this could take much longer than their ideal given the complexities and challenges that could arise.[1229]

Figure 91: Ideal timeframe for moving to a new living arrangement, share of total surveyed[1230]
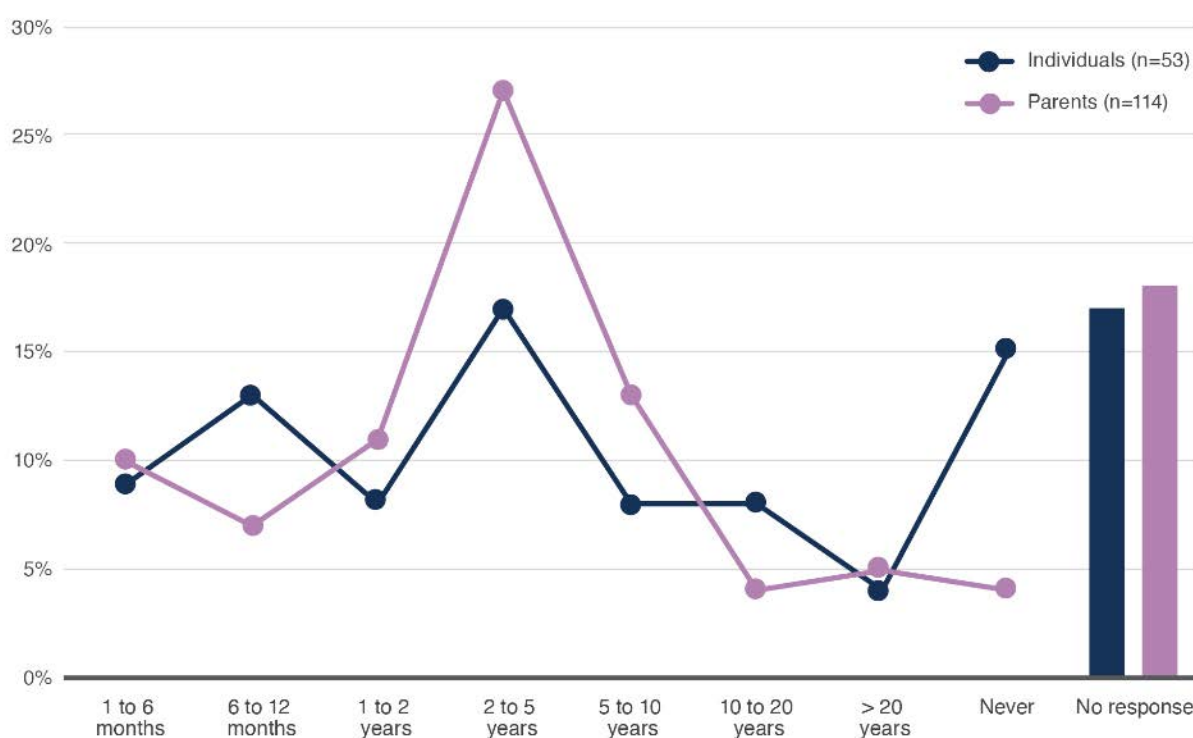
3.2.3. Access to independent, specialist advice on housing and living supports is essential

More time to explore housing and living options is often not sufficient. Housing and living supports that are funded by the scheme can be confusing and difficult for most people to understand. For many participants, they can be complex to navigate, along with the range of housing options available in other service systems.[1231]

Access to more information is crucial. We have heard evidence that there needs to be greater access to clear and accessible information about housing and living options for participants.[1232] Without this information, participants are unable to make informed decisions.[1233] For example, Queenslanders with Disability Network (QDN) suggested an 'information kit' could be provided to people navigating housing options, which could include information about housing models and detail what they offer, what they look like as well as examples of people's experiences of living in each form of NDIS accommodation.[1234]

However, the NDIA's 2021 *Home and Living Consultation Summary Report* found that information alone would not be enough for most participants to make informed decisions about their home and living supports. Of the participants surveyed, around a quarter said they also need someone to talk through their options with them, and a similar number said that they would benefit from examples of what home and living support solutions have been used by others.[1235]

To date, participants have largely relied on their existing Support Coordinator for this advice and help, though with varying results. For some, the participant's Support Coordinator played a vital role in helping them to get the housing and living supports they need – usually where the Support Coordinator had specific housing and living expertise and knowledge. At the same time, many participants do not have the housing and living supports they need, or have concerns about the quality and safety of their housing and living supports.

We heard of the need for Support Coordinators, NDIA planners, Local Area Coordinators (LACs), Plan Managers, and service providers to have specific training, and enough time to work directly with participants and their families or carers to understand and explore home and living options.[1236]

> *"It is important that participants have access to trained specialist home and living support. Trained specialists are supporters with experience and expertise in disability and housing, knowledge of the local community and connections with community, mainstream and social housing networks, tenancy supports, advocates and providers."*
> *– NDIA's Having a Go Report*[1237]

The existing NDIS Code of Conduct requires all registered and unregistered providers to act with integrity and manage their conflict of interests. However, specific concerns have also been raised about Support Coordinators not acting in the interests' of the participant and their family members, particularly where a Support Coordinator is employed by a provider who also delivers SIL and/or SDA.[1238]

Approximately 5-10 per cent of all participants who received intermediary supports during the quarter ending 30 June 2023 are accessing all their supports from a single provider.[1239] This includes a small, but concerning, number of participants where their provider is also delivering their SIL and/or SDA supports. In addition, approximately 20 per cent of participants who received intermediary supports in the quarter ending 30 June 2023 have more than one provider, but have the same provider delivering their intermediary and at least some of their other supports.[1240]

In some cases, information and advice have been withheld, or curated in such a way to lead participants to make decisions which puts the Support Coordinator's or the housing provider's interests ahead of those of the participant.[1241] Some participants may also be reluctant to, fearful of, or potentially prevented from, raising concerns about the quality and safety of their housing and living supports with their Support Coordinator.

As a result of these types of concerns, in May 2020, the Joint Standing Committee on the NDIS recommended that the NDIA implement a mechanism to separate service delivery, tenancy management and support coordination for participants in SIL settings.[1242]

We believe that specialist independent advice is essential for participants in exploring housing and living options and exercising genuine choice and control. This was strongly supported by submissions to this Review.[1243]

To effectively support the participant and their family to make an informed decision about their housing and living supports, this advice and help has to be provided by someone who:

- possesses in-depth knowledge about the wide range of housing and living supports, both funded by and outside the NDIS
- has the necessary skill and expertise in navigating the broader housing system
- is independent of service providers and therefore has no vested interest in the participant's decision about their housing and living supports.

We have heard a number of suggestions on who and how this advice and help should be provided. These included:

- assisting Support Coordinators to build housing and living expertise and recognise their specialisation in delivering targeted home and living support coordination[1244]
- leveraging the expertise of registered community housing organisations to assist people with disability and their families to navigate the housing system – including public housing, community housing, the private rental market, home ownership and disability-focused housing programs (such as SDA)[1245]
- introducing a dedicated role within the NDIA to assist with sourcing housing and educating the sector[1246]

More innovative solutions also currently exist, which could be leveraged. For instance, the Housing Hub uses an online platform to provide a way to match housing seekers with housing providers, to share information and resources and to provide advice on NDIS housing supports.

> **Case Study 20: The Housing Hub**[1247]
>
> The Housing Hub is a disability housing online platform which currently has over 3,500 listings for a range of housing options – such as existing SDA, new SDA builds, non-SDA supported accommodation, private rental, and private properties for sale. The platform is free for both housing seekers and housing providers and was reported to have over 17,000 monthly active users. Last financial year, the Housing Hub advised that their team had supported over 700 people to find new homes.
>
> In addition to its online platform, the Housing Hub provides a range of information and support to help people with disability consider housing options and plan their move. These include a library of over 150 resources, free weekly events and an NDIS Housing Advice Line.
>
> The Housing Hub also recently piloted a "Home and Living Specialist" service, which supported participants with complex needs living in residential aged care, group homes and in hospital to explore alternative housing options. These specialists were highly skilled with expert housing knowledge and independent of support providers. The workforce involved in the pilot were also trained in supported decision-making to enable them to assist those with severe cognitive and communication impairments.
>
> The Housing Hub was created by the Summer Foundation as a pilot project in 2017 with funding from the Department of Social Services (DSS) Sector Development Fund. At the time of writing, the Housing Hub was a subsidiary of the Summer Foundation. However, they have reported that in 2023-24, the Housing Hub will become a separate charity and a Disabled Persons Organisation with more than 50 per cent of board members with lived experience of disability. The Housing Hub team already has 40 per cent of employees with lived experience of disability.

In considering these suggestions, we have had to balance how participants could access specialist advice and help for exploring housing and living supports without causing further confusion and complexity in navigating the broader scheme.

We know that the introduction of the current intermediary roles has only caused more confusion, so introducing more roles should be done with caution. In getting support to navigate the broader scheme, we heard that participants really want someone who has knowledge about their local community and with whom the participant can build an ongoing, trusted relationship (see Chapter 2). This is particularly important for housing and living decisions – which are not simple short-term transactions, but are fundamental to a participant's needs, preferences and goals.

We recommend that all participants should have access to a Navigator to help plan and access their supports (see Action 4.1). However, building housing and living knowledge and expertise for all Navigators would take considerable time and resources, and would be inefficient since participant demand to explore housing and living solutions fluctuates greatly over the participant's lifetime. Such an approach would also likely be ineffective as information needs to be up-to-date and so requires ongoing focus.

Instead, we proposes a model where specialist housing and living expertise and advice can be drawn upon by the participant and their Navigator as needed in different points in their life. Similar to how a general medical practitioner would draw on the advice of medical specialists, the General Navigator remains the participant's key point of contact and primary person responsible for helping the participant navigate the scheme (see Action 4.1), while a Housing and Living Navigator acts as a consultant for the participant and their Navigator.

The General Navigator would consult the Housing and Living Navigator's expertise early as the participant and their families begin thinking and planning ahead for their future housing and living needs and preferences (Figure 92). This will ensure that any change in housing and living arrangements at key life stages is explored, designed and planned well in advance of a change. The participant may not necessarily have a housing and living support budget at this point in time, but access to something like a budget ready reckoner will help to facilitate this effectively and ensure that these discussions are bounded with realistic expectations.

As the participant progresses in exploring their housing and living support options, the participant and General Navigator may then need more hands-on help from the Housing and Living Navigator. For instance, the Housing and Living Navigator will likely need to be more active and involved in supporting the participant to try out alternative housing and living arrangements (see section 0). The Housing and Living Navigator would also lead work with the participant and general Navigator in designing and implementing the participant's new housing and living arrangements once a housing and living budget has been received.

To perform these functions, the Housing and Living Navigator would require knowledge of the full range of NDIS housing and living supports, including provider options in the participant's local area, and skills at negotiating with service providers to implement a participant's preferred arrangement within the constraints of the participant's budget. Part of their role would also entail the translation of knowledge and diffusion of best practice and innovative housing models, to encourage the uptake of more effective and diverse options (see section 4.1).

As noted above, it would be impractical to require every General Navigator to have specialist housing and living expertise. Nevertheless, we can envisage scenarios where a General Navigator with the requisite skills and knowledge would perform both roles, particularly where the same organisation is delivering both services in a particular area. In this scenario, the support would be in addition to, rather than in lieu of, the general navigation support.

Figure 92: How participants would be supported by their Navigator with support from a Housing and Living Navigator function to explore housing and living support options

1. Identify housing and living needs

- **Navigator** works with the participant and their family to determine their housing and living needs and preferences. Where possible, this would be done early to begin preparing and plan for possible changes throughout their life stage.

- In doing so, **Navigator** might consult or seek advice from a **Housing and Living Navigator** as needed.

2. Explore housing and living support options

- Working with the **Housing and Living Navigator**, the **Navigator** would take the lead in helping the participant and their family to understand and explore the range of available housing and living support options.

- Where appropriate, the participant may need funding to trial different housing and living support options.

  - **Housing and Living Navigator** would provide information and advice to the NDIA to determine funding needed for trial.

  - **Navigator** would be responsible for helping participants to use their funding and coordinate their supports to trial different housing and living support options.

3. Design and set up housing and living solution

- **Housing and Living Navigator**, working with the **Navigator**, would help the participant and their family in considering what housing and living support works best for their circumstances, needs and preferences.

- NDIA would provide funding for housing and living supports that best meet the participant's needs. Decision would be informed by information and advice from the **Housing and Living Navigator**, and result from participants trying different options, where applicable. Once funding is received:

  - **Housing and Living Navigator** would work with the participant's **Navigator** and chosen provider(s) to help design and setup the participant's housing and living solution. This includes monitoring and adjusting as needed to ensure the housing and living solution works for the participant.

  - **Navigator** would help the participant adjust and arrange their other supports. This includes working to build the participant's capability to safely and confidently live at home, with as much independence as possible.

3.2.4. Trialling alternative housing and living arrangements will build confidence

Opportunities to try housing and living options is often critical in supporting participants to effectively explore and choose housing and living arrangements that work for them. Trialling alternative arrangements helps participants to understand how different housing and living options would work for them, builds capability and confidence in making choices about their housing and living arrangements, and encourages uptake of any new arrangements.

Historically, there has been a lack of choice, especially for participants transitioned from state and territory systems who have lived in their current setting for long periods and do not know what possible options exist.[1248] We refer to this group as 'transitioned participants' (see Box 44). There has also been a lack of choice for those living with ageing parents. Long waiting lists in the previous state and territory systems is often why they are at home. We heard that many of these participants have never been given the opportunity to explore and trial housing options.[1249]

Participants who live in group homes are unable to move out for any length of time without jeopardising their placement in their existing residence, and their funding for needed supports is typically tied into those arrangements for the length of their plan.[1250] The assessment process is opaque and difficult to navigate, creating uncertainty and a barrier to people feeling confident to change their existing arrangements.[1251]

Participants seeking to transition out of aged care or hospital settings also face barriers to trialling different accommodation options. We have heard there is confusion surrounding who is responsible for providing the funding and support, arranging transport and assuming the liability for participants looking to trial housing options.[1252]

There is widespread support from participants, advocates and providers for funding to enable trialling of new arrangements:

> *"'Try before you buy.' People with disabilities should not necessarily be 'shoehorned' into a decision that does not leave room for change or adjustment. So, opportunities need to exist for try 'before you buy'" – Autism Family Support Association[1253]*

> *"Exploration and design funding is an avenue to give NDIS participants the opportunity to try out different living options. This is particularly important for people with disability who have never had the opportunity to experience something different other than living in institutions, or group homes." – Queenslanders with Disability Network[1254]*

> *"We also used to have a unit that was specifically for people to come and practice their independent living skills, so they could stay for a weekend or a week and would have specifically designed training programs while they were there as a transitional approach, to assess their ability for what kind of living situation might suit them, but also to help them build their skills along the way." – Provider[1255]*

The ability to trial arrangements before a move is likely to increase a participant's confidence, shift expectations and helps them to understand what best meets their needs.[1256] Trialling different living options supports NDIS participants to determine their preferences and experience a variety of options. Adequate and well supported transition time is also necessary.

We believe that detailed consultation with the sector is required to develop the optimal design for trialling arrangements and should consider a range of matters, including:

- When a participant is eligible to take part in a trial (for example, only at specific life-stage transition points), the duration of the trial, and the number of times any individual participant can participate in a trial.
- What supports are available during the trial and how these should be funded. Given the intent of a trial is that a participant can revert to their existing arrangement should it not be successful, there will need to be consideration as to how the existing arrangement can be preserved. In cases where this involves the participant currently living in an SDA dwelling and/or an existing shared living arrangement, any SDA and/or 24/7 living support vacancy in the existing arrangement will need to be funded for the duration of the trial.
- How to ensure effective matching for the short-period of the trial. However, it should be noted that the trial also represents an opportunity for an existing resident group who are sharing supports to assess whether the new participant is a good match for a longer-term living arrangement.

3.2.5. Some groups are in particular need of a reassessment of need and support to explore alternative arrangements

We believe there are two groups that should be prioritised for reassessment of their needs and given supports to explore their options and trial alternatives – transitioned participants and participants living with ageing parents.

Transitioned participants

As noted in Box 44, transitioned participants have been particularly disadvantaged in their funding allocations since entering the scheme. In addition, many have a lived experience of institutionalisation. This is due to the fact that most pre-NDIS state and territory disability accommodation services were group homes, which were established as an alternative accommodation option for people following the closure of large residential institutions from the late 1980s onwards.[1257] As a result, some transitioned participants have lived their entire lives in some form of institutionalised arrangement and have never been given any meaningful opportunity to have a say over where, how and with whom they live.

For this reason, we believe this group should be prioritised for a reassessment of their housing and living goals and needs, and support to imagine, explore and try new housing and living arrangements. This could be an effective antidote to this historic denial of choice. Importantly, any engagement with this group must recognise that choosing to remain in their existing arrangement is just as valid a choice and should be respected and supported (see section 4.3).

Adults living with ageing parents

Adults living with ageing parents should also be prioritised for reassessment of their housing and living goals and needs.

Across Australia, there are many parents who provide a significant amount of informal support to their adult child – in effect, taking on the role of a primary carer. However, as parents age and begin to require care themselves, their ability to sustain this level of informal support comes under pressure. In some cases, a parent's capacity to provide any informal support may end suddenly, for example, if they experience a catastrophic ageing-related illness such as stroke. This can lead to crisis-driven solutions, with the urgent need to find any housing and living arrangement for the participant taking precedence over ensuring its quality and appropriateness.

Ageing carers face a mix of challenges in exploring housing and living solutions for their adult children with disability. A 2012 UK study identified several barriers that contributed to a reluctance on the part of ageing carers to plan for transition, including limited confidence in the quality of alternative formal supports, a lack of information, and finding it to be a difficult and emotive subject.[1258] We received many submissions reflecting these findings in the Australian context.[1259] We heard that ageing parents are concerned that their child's plan does not adequately consider the consequences of the parent's unplanned hospitalisation, admission to residential aged care or death.[1260]

We have also heard that there can be a reluctance on behalf of the NDIA to support a change that would substantially increase the participant's plan costs, compared to them remaining in the family home and receiving high levels of informal support.[1261]

> *"My autistic son is approaching middle age and I am approaching old age. He resides with me in the family home that is set up to meet his social, sensory, special interest and care needs. He is happy and settled and assisted by carers funded by his NDIS plan. But I fear for his future welfare and well being. What happens if I need aged care? What will happen to my son even if he can stay in the family home? Or worse, if he is required to move elsewhere? No one can satisfactorily answer these and my many other questions. As a family we have no reassurance of 'a system' ready to step in. His NDIS plan has no mention of his future needs. What will he qualify for?" – Autism Family Support Association[1262]*

Given these challenges, and in recognition that well-planned and supported solutions can take 2-5 years to plan for and will always be better than crisis-driven approaches, we believe adult participants living with ageing parents should be prioritised for a reassessment of need and to explore and trial alternative living arrangements.

Currently the NDIA has limited visibility on the number of participants living with ageing parents. Addressing this lack of data is an essential first step to ensuring these participants can access the support they need and give much-needed comfort to their loved ones that their child will be supported once they are no longer able to support them.

3.2.6. Action & Implementation Details

Action 8.2: The National Disability Insurance Agency should commission a Housing and Living Navigation function to provide advice on participants' housing and living options

Participants and Navigators (see Action 4.1) should have access to advice from an independent Housing and Living Navigator with specialist expertise in the range of local housing and living supports. The Housing and Living Navigator should work with the General Navigator (or this could be the same person) to support a participant to explore the range of housing and living options available and understand what options align with their preferences and provisional NDIS budget. They should also help participants connect with suitable providers to identify new living opportunities or those with vacancies. This approach should ensure any change in housing and living arrangements at key life stages is explored, designed and planned well in advance of a change.

Implementation detail:

- In commissioning the Housing and Living Navigator, the NDIA should specify that the skills, knowledge and functions for this role include:

  - knowledge of the full range of NDIS housing and living supports, including provider options in the participant's local area

  - skills at negotiating with service providers to implement a participant's preferred arrangement within the constraints of the participant's budget

  - ability to translate knowledge and diffusion of best practice and innovative housing models, to encourage the uptake of more effective and diverse options (see Action 9.1).

- The NDIA should work with the new National Disability Supports Quality and Safeguards Commission to ensure that the Housing and Living Navigation function is regulated in a way that is consistent with the regulatory model outlined in Recommendation 17.

Action 8.3: The National Disability Insurance Agency should design, fund and implement a process for participants to try new living arrangements at key life stages, before they commit to them

A process for participants to try new living arrangements should be designed to help participants feel more comfortable with any move into a new arrangement. This should encourage participants to try diverse, innovative options that are more inclusive and contemporary and reduce the cost of poor matching and housing outcomes. The process should be designed and trialled with people with disability and the sector before being rolled out. Priority for taking up this opportunity to trial new arrangements should be given to

those living with ageing carers and in ageing Specialist Disability Accommodation (Legacy and Basic) dwellings.

Implementation detail:

- In the design of the process, the NDIA should work with the sector and people with disability to consider:

  - what types of supports should be offered, who should be eligible for the support and when (for example, at which key life stage transition points), and over what time-limited period

  - how to ensure that effective matching of participants trying new living arrangements for a short period can be achieved. This should look to minimise the risks for matching incompatibilities in short-term arrangements

  - options for funding participants for the trials

  - how the vacancy in a participant's existing living arrangements (for Specialist Disability Accommodation if applicable, as well as 24/7 living supports) will be funded for the period in which they are trying the new arrangement.

3.3. In shared living settings, more coordination of shared supports is needed to drive better outcomes

We have heard that many shared living settings are characterised by semi-institutional cultures, where the rhythm of everyday life is dictated by staff and service providers, rather than directed by the participants who call it home. While there are some examples of effective participant-led governance in shared living settings, these generally rely on active and engaged family or other informal supporters – a resource not universally held by all participants. For those without informal supports, limited formal mechanisms to coordinate participant interests act as another barrier. All participants funded for shared supports should have a say in the governance of their shared living arrangements, irrespective of their level of access to informal supports.

3.3.1. Joint decision making on shared supports can drive better outcomes

In many shared living arrangements, the voice of the individual participant is not heard or supported and their preferences are not always understood or balanced with those they share with.[1263] Many submissions also told us that participant preferences are often secondary to the needs of the service provider delivering shared supports.[1264]

The Young People in Nursing Homes National Alliance (YPINHNA) highlighted how shared settings are "crowded spaces with multiple therapists, support coordinators, families, advocates and provider staff," and as a consequence of these features:

"No one is in charge of coordinating the various interest groups and achieving agreed outcomes; there is no oversight or coordination of participants' support and service needs; and identification of changes in support need simply don't happen. The legacy model of provider control in these shared settings has not only survived but, following transition to the NDIS SIL funding model, has thrived anew." - YPINHNA[1265]

"For participants moving into a shared living arrangement, current SIL procedures have no transition process wherein time and support is provided to the participant and their support network to indicate their specific needs and consider their wishes and preferences regarding their new living arrangement. New members of the household are simply expected to fit in to the existing model. So too, once participants are in a shared service, there is no formal mechanism whereby they can negotiate with each other or with the provider about the support being delivered." - YPINHNA[1266]

Providers can, and do, perform a facilitation function, for example, incorporating a participant's individual funding package into a shared support roster. However, they can face limited or competing incentives to act in the interests of participants, such as financial pressure to fill a vacancy quickly with limited regard to the preferences of the existing resident group.

Individual participants within a resident group may also have varying levels of access to resources, including informal supports, leading a provider to preference the needs of those individuals relative to others in the group. While other formal supports, such as Support Coordinators, could play a more active role, this is complicated by participants having different Support Coordinators who often do not work collaboratively to address shared problems.

While not widespread, we have heard of innovative shared household governance models which are led by participants, their families or other supporters, such as the Supported Independent Living Cooperative (SILC) (Case Study 21). In these participant-led governance models, decisions on daily routines, activities, household management and staffing approaches are made collectively by residents or their supporters and negotiated with the service provider. This could be something as simple as determining weekly meals or an agreed process or longer timeframes to fill a vacancy when a resident leaves the arrangement.

Given that around 80 per cent of participants funded for 24/7 living supports have a disability that could affect their decision-making capacity (for example, intellectual disability, autism, acquired brain injury or psychosocial disability), these models generally rely on active and engaged family members. However, for those without robust informal support networks, relying on other formal supports to perform this role poses challenges.

We believe that all participants funded for shared supports should have a say in the governance of their shared living arrangements, irrespective of their level of access to informal supports. To level the playing field, we recommend the introduction of a new shared support facilitation function that is completely independent of the shared support provider, and property management and SDA providers.

The core purpose of this function would be to work with the participant group sharing supports, including their informal supporters, to design a shared service model within the bounds of their shared budget. This would be collectively agreed to by the group. We envisage that this could cover a range of matters, including, but not limited to:

- The scope of shared services, including respective funding contributions from each individual participant.
- The roles and responsibilities of the support provider and the accommodation provider.
- Mechanisms for input into staffing and rostering decisions and the overall culture and values of the home.
- Vacancy management processes.
- Dispute resolution procedures.

Once agreed to by the participant group, it would be the responsibility of the person performing the shared support facilitation function to assist the group to negotiate with the support provider to implement the model. While establishing the service model and negotiating its implementation would be the most resource-intensive task, there would be an ongoing need for the person performing this function to monitor the arrangement, resolve disputes and build the capacity of the group to self-advocate for adjustments. They would also need to be called on again to make adjustments when the participant group changes due to resident turnover.

There appears to be appetite within the sector for this type of approach. In late 2022, the Housing Hub convened a series of workshops to explore how ageing group homes could be transitioned to contemporary shared living arrangements. These workshops included a range of stakeholders, including service providers and impact investors that collectively provided, managed or financed 750 properties for NDIS participants, representing 2,400 places.[1267]

The outcome of these workshops were summarised in a February 2023 report, with a key recommendation being the development of "independent governance models for shared living to facilitate supported and collective tenant-led decision making in shared living arrangements, ensuring tenant control over how they live (with who, how they are supported and what happens in their home)".[1268] Three of the service providers who participated in the original workshops — Yooralla, Cerebral Palsy Alliance and Life Without Barriers — have subsequently commissioned further work on how this and other principles could be tested through a demonstration project.[1269]

Other organisations are implementing this approach at a small-scale. Enliven Community is an independent charity associated with SDA provider Enliven Housing. They have developed the concept of a "community cooperative" which they describe as "a community of people who live in the same apartment complex, town house or share house, who voluntarily choose to share the cost of the on-site support with other tenants with disability".[1270] Each community cooperative is supported by an independent facilitator and at the time of writing, Enliven Community reported working with 17 community cooperatives.[1271] YPINHNA also advised us that they were trialling the use of a dedicated independent facilitator to support shared decision-making and participant-led governance at five sites in New South Wales and Victoria.[1272]

We believe there are two options for the delivery of the new shared support facilitation function.

- The first would see the function performed by the General Navigator. While this approach avoids the creation of an additional intermediary, it essential that the person performing this function be the same for all participants in the shared arrangement. As such, this approach would require all participants to align their General Navigators. This has the potential to disrupt long-established relationships and may act as a barrier to participants choosing the most appropriate shared support arrangement on offer if the consequence of that choice is the loss of their existing General Navigator.
- The second option would see this function performed by a discrete "Shared Support Facilitator". While avoiding the potential disruptions of the first option, this approach adds additional complexity and creates the possibility for role confusion. It also creates additional costs and assumes the availability of a suitably skilled workforce.

We believe that in designing this function, the NDIA should allow for both options, in line with the wishes of the group of participants sharing supports. For the function to work as intended under either approach, it requires a person well-versed in supporting people with disability, supported decision-making (see Recommendation 5) and service delivery. They would also need to possess skills in facilitation and mediation. Most critically, they would need complete independence from the shared support, property management and SDA providers and to act in the best interests of the participant group.

3.3.2. Action & Implementation Details

Action 8.4: The <u>National Disability Insurance Agency</u> should commission a shared support facilitation function to empower participants sharing supports to exercise joint decision-making

A shared support facilitation function should be introduced for participant groups sharing supports, as well as their families and/or other representatives, to embed participant-led household governance in shared arrangements. This should involve designing, negotiating, monitoring and implementing an agreed model for shared support delivery for the group. This function should be independent of the support provider and property manager.

Implementation detail:

- The NDIA should, together with participants, the sector and relevant professionals, design and outline the functions for the Shared Support Facilitator, including:

    - Working with participants and providers to design a shared service model that is clearly documented through a service agreement, and understood and agreed to by all participants at the commencement of the shared support arrangement (or amendment, in the case of a new participant entering into an existing shared arrangement).

- o The shared service model may cover a range of matters including, but not limited to, the scope of shared services (including respective funding contributions from each individual participant), process for input into staffing and rostering decisions, vacancy management processes, and dispute resolution mechanisms.
  - Negotiating with the provider to implement the shared service model, monitor implementation and mediate any disputes.
  - Building the capacity of the participant group and/or their informal supporters to self-advocate for adjustments to the shared service model.
  - Supporting the safety and wellbeing of residents in the shared arrangement.
- In designing this function, the NDIA should allow for the role to be delivered by a General Navigator, common to all household members, or for it to be a discrete function that sits alongside each participant's General Navigator.
- The NDIA should work with the new National Disability Supports Quality and Safeguards Commission to ensure that the shared household facilitator is regulated in a way that is consistent with the regulatory model outlined in Recommendation 17.

4. Delivering a diverse and innovative range of inclusive housing and living supports

- Despite good intentions when the scheme was introduced ten years ago, there has been limited change and innovation in the way housing and living supports are provided.
- Outdated congregate care settings still dominate and the Specialist Disability Accommodation (SDA) market is not always delivering the right houses in the right locations.
- A wider range of housing and living supports that are better tailored to the diverse needs and circumstances of participants would enable the NDIS to deliver on its promise of supporting the social and economic participation of people with disability, promoting better inclusion and outcomes, and giving participants genuine choice.
- Achieving this will require more effective market stewardship and intergovernmental collaboration.

Recommendation 9: Deliver a diverse and innovative range of inclusive housing and living supports

📃 Legislative change required

- Action 9.1: The National Disability Insurance Agency, in collaboration with the new National Disability Supports Quality and Safeguards Commission, should invest in the collection and dissemination of housing and living data and analysis.

- Action 9.2: The National Disability Insurance Agency should implement a new funding approach for participants sharing living supports to strengthen the focus on service quality and outcomes.
- Action 9.3: The National Disability Insurance Agency should release more detailed and frequent information on participant demand for 24/7 living supports and Specialist Disability Accommodation (both medium and longer term needs).
- Action 9.4: The National Disability Insurance Agency should remove the Improved Liveability category for new Specialist Disability Accommodation (SDA) developments, and review the remaining SDA categories and associated Design Standards to evaluate their effectiveness.
- Action 9.5: The Australian Government should transition responsibility for advising on Specialist Disability Accommodation pricing to the Independent Health and Aged Care Pricing Authority and introduce more flexibility to the way prices are set.
- Action 9.6: The National Disability Insurance Agency, in consultation with state and territory governments, should commission Specialist Disability Accommodation where needs are not adequately met by the private investor model.
- Action 9.7: The new National Disability Supports Quality and Safeguards Commission should strengthen Specialist Disability Accommodation (SDA) regulation to ensure dwellings are managed in accordance with the needs of participants and mandate the separation of SDA and living support providers.
- Action 9.8: All Australian governments should agree and implement an intergovernmental strategy for upgrading or repurposing ageing Specialist Disability Accommodation stock owned by states and territories.
- Action 9.9: The National Disability Insurance Agency should amend its change of circumstance and Specialist Disability Accommodation (SDA) policies to reduce the bedroom count of ageing SDA dwellings.
- Action 9.10: The National Disability Insurance Agency should introduce a new Specialist Disability Accommodation (SDA) category for participants funded for shared living supports but not eligible for existing categories of SDA.
- Action 9.11: All Australian governments should agree and publish a targeted action plan for housing under Australia's Disability Strategy.

4.1. There has been little diversity and innovation in housing and living supports

Although a decade has passed since the NDIS commenced, most housing and living support options look similar to pre-scheme arrangements.[1273] Four and five bedroom group homes still dominate the built environment and, despite pockets of innovation, service models appear relatively unchanged. This leaves participants with little choice. There are many barriers to greater diversity and innovation, including incomplete and inadequate data on best-practice housing and living supports and ineffective market stewardship.

4.1.1. Current arrangements are limited in choice

Group homes and legacy stock dominate the accommodation landscape

While data on the living arrangements of participants is poor (see section 2.3), SDA dwelling enrolment data sheds some light on the most common accommodation options available. At the end of June 2023, almost a third (30 per cent) of all enrolled SDA dwellings were either a group home (4 or 5 residents) or Legacy stock (6 plus residents) (Figure 93). Combined, these dwellings represent more than half (55 per cent) of all SDA places. This is likely an undercount, as it assumes that each Legacy stock dwelling has a maximum of 6 places.

Figure 93: SDA dwellings and places at 30 June 2023 by dwelling type[1274]
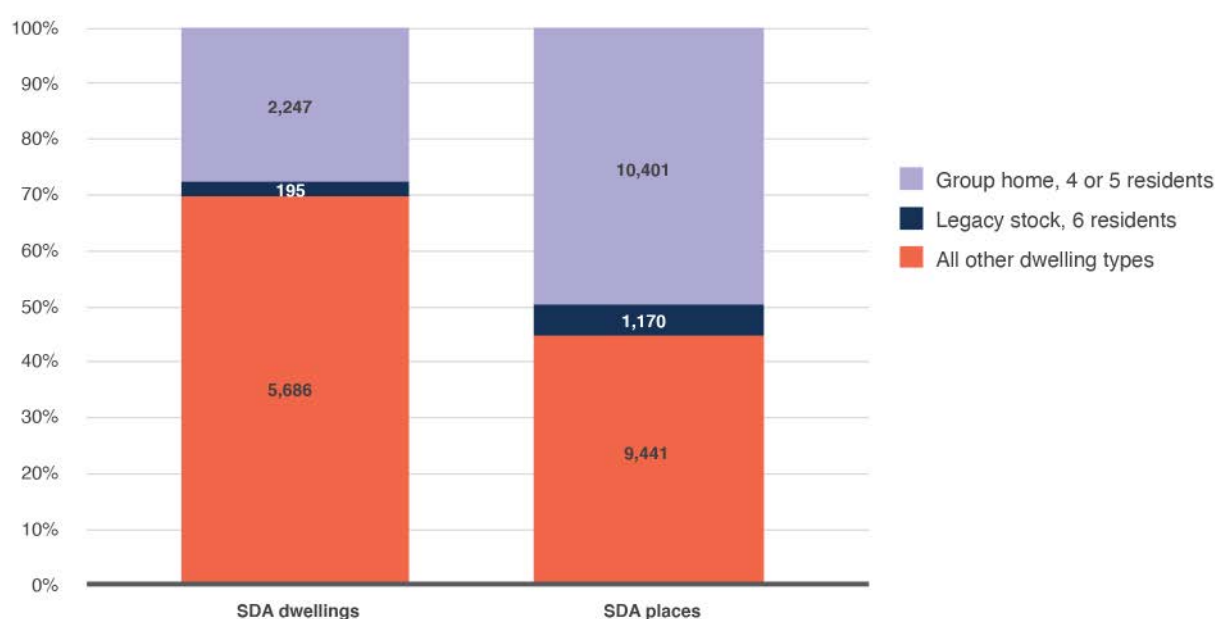
The disproportionate availability of SDA places in these types of dwellings has, unsurprisingly, resulted in large numbers of participants living in them. At 30 June 2023, 11,893 participants could be exactly matched to living in an SDA dwelling, with around two-thirds (67 per cent) living in one of these dwelling types.[1275]

We have heard that support arrangements in these larger settings are often semi-institutional in nature, where participants have limited say over who they live with and where the culture is more akin to a workplace than a home.[1276] The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) also heard evidence that group homes can be like institutions, and that people with disability living in these arrangements often have limited choice over where and with whom they live.[1277] Dr Colleen Pearce, the Victorian Public Advocate, gave evidence to the Disability Royal Commission about the need for service providers to "find the balance" between organising a group home as a workplace and as a home, and that this tension will also "be inherent in other models where people require support".[1278]

Living supports are dominated by SIL and uptake of ILO has been limited

There is very little on offer to participants requiring 24/7 supports outside of Supported Independent Living (SIL). But the way that SIL is delivered, and the setting in which it is delivered, has largely not evolved since the inception of the NDIS. There continues to be a lack of focus on capacity building and independence, and on supporting participant groups sharing support to exercise joint decision making.

Following its July 2020 introduction, the National Disability Insurance Agency (NDIA) placed a high emphasis on Individualised Living Options (ILO) as an alternative to SIL supports in an attempt to modernise living support offerings. However, the ILO Operational Guideline specifically notes that it is unlikely to be suitable for participants requiring 24/7 rostered support or frequent overnight support, despite these being two of the key features that characterise eligibility for SIL support.[1279]

Uptake of ILO has been minimal. As noted in Box 42, ILO is funded in two stages. However, it appears that few participants progress beyond the initial exploratory phase. Of the 1,344 participants who claimed a payment for 'ILO – Exploration and Design' in 2022-23, only 55 (4.1 per cent) also claimed a payment for the second stage 'ILO – Support Model' in the same period.[1280] While it is possible that some of these participants may progress to the second stage over the course of 2023-24, overall uptake remains low, with only 747 participants claiming a payment for ILO – Support Model in 2022-23.[1281]

Recently, the NDIA found that some participants claiming ILO payments had arrangements that were effectively paid rostered supports, indistinguishable from SIL arrangements. In the 18-month period between 1 July 2021 and 31 December 2022, 132 participants accessing ILO were reclassified to SIL by the NDIA.[1282]

Being individualised in nature means that each ILO is unique. However, they are distinguished by two components — primary and supplementary supports, which are funded at three different levels (Figure 94) to cover different support needs.

Primary supports refers to an unrelated person that lives with the participant and provides most of their living supports. This can take the form of a host arrangement (where the participant lives in the home of an unrelated host) or a housemate arrangement (where the participant lives in their own home, or shared rental property, with one or more other unrelated people).

Supplementary supports refer to additional supports that can either be formal or informal, which can be used to substitute the primary support when they are not available and/or provide extra assistance.

Figure 94: The NDIA funds three levels of ILO – Support Model and provides guidance on what can be expected from primary and supplementary supports at each level[1283]

Support level	Funding amount	Overview of primary supports	Overview of supplementary supports
Level 1	Up to $105,000	Provides companionship and **some casual direct support** This may involve prompting with personal care, household tasks and help to manage emotions and behaviours	Drop-in or on-call support, regular time with family or formalised assistance from a neighbour
Level 2	Up to $150,000	Provides companionship and **more regular direct support** This may involve physical assistance with personal care, supervision of household tasks and help with supporting behaviour	Paid drop-in support, on-call support, structured informal support from family or friends, formalised support from a neighbour or mentor
Level 3	Up to $230,000	Provides companionship and **sustained direct support** This is likely to involve physical assistance and personal care, direct supervision of household tasks, help with supporting behaviour and potentially disability-related health supports	Everything described in Level 2 as well as an alternative primary support to provide relief assistance for the person providing regular primary support

4.1.2. There are pockets of housing and living innovation and best practice

While there has not been a flourishing of diverse housing and living options, pockets of innovation have emerged over the past decade.

Some innovations have occurred in how supports are organised, such as the development of participant/family-led governance structures. These are typified by active and engaged families who work with participants to ensure they are living with people they have chosen and ensure supports are delivered in accordance with the wishes of residents and not dictated by service providers. An example of this approach is the Supported Independent Living Cooperative (SILC).

Case Study 21: Supported Independent Living Cooperative (SILC)[1284]

SILC was established in September 2016 to connect and support families of participants to form and operate small, family-governed share houses as an alternative to the traditional provider-led group home model.

SILC supports the parents and siblings of a group of participants who will be living together and sharing supports to create a legally incorporated entity in the form of a cooperative, known as a House Operator. The House Operator is responsible for interviewing and selecting a house manager, who is a paid worker that supports the family to recruit staff and develop rosters.

SILC is the legal employer of the staff chosen by the House Operator, managing payroll and other human resource functions. SILC is also a registered NDIS service provider, with regulatory obligations to the NDIS Quality and Safeguards Commission (NDIS Commission) and also develops and maintains policies and procedures. Ultimately, the House Operator, i.e. the family co-operative is the service provider, with SILC providing operational and administrative support and guidance.

In a meeting with the Review, SILC advised that dwellings are usually owned by an external landlord and the House Operator is the tenant responsible for paying rent.

As of October 2023, SILC was supporting the operation of 12 homes in New South Wales.

The SILC model, by its nature, relies on very active and engaged family members. When appearing before the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), the CEO of SILC acknowledged that the families participating in the SILC model were generally socioeconomically advantaged, which supported the application of the model.[1285] However, as discussed in section 3.33, we believe the essential elements and benefits of this model can be scaled with the introduction of a Shared Support Facilitator function.

Other innovations have been in the built environment, with the deliberate design of co-located homes that offer individual privacy and autonomy but still facilitate effective sharing of supports. An example of this approach is the Haven model, which the Productivity Commission in its 2011 report, *Disability Care and Support*, identified as worth pursuing.[1286]

Case Study 22: The Haven Foundation[1287]

The Haven Foundation is a community housing provider and subsidiary of Mind Australia, a registered NDIS provider.[1288] Together, they deliver an integrated social housing and 24/7 on-site shared living support model designed for participants with psychosocial disability. These are known as Havens.

Haven residences feature up to 16 private apartments, each with its own bedroom, kitchen, living room, bathroom, laundry facilities and private outdoor area. Residents live in their own apartment, which encourages independence, choice and control, and provides comfort and

security. Each Haven also includes large indoor and outdoor shared communal areas. Residents are not obligated to use these spaces, however, they facilitate opportunities for social connection and peer-support.

In 2013, Monash University conducted an independent evaluation of the Haven in South Yarra, Melbourne, which found that residents had a reduced need for acute psychiatric care, had increased participation in vocational education and training, and improved connections with family members and the broader community.[1289] Another independent evaluation is currently being conducted by La Trobe University, with preliminary results indicating residents had improved their independence and saw reductions in symptoms of mental distress.[1290]

Participants enter into a residential tenancy agreement with The Haven Foundation and an NDIS Service Agreement with Mind Australia. While this creates separation between participants' housing provider and support provider, those who choose to live in a Haven must use Mind Australia to deliver their 24/7 living supports. Without this requirement there would be no practical mechanism to share living support costs across participants.

Combining housing with support acts as a mechanism to increase affordability for participants, increasing the accessibility of supported housing for this group. Funding from the Victorian Government provides capital to develop purpose-built residences which are managed by The Haven Foundation, with psychosocial support provided on-site by Mind Australia. The capacity to combine housing and support also creates a financial environment where innovations such as Haven can exist. Mind Australia have told the Review that an inflexible separation between housing and support would undermine the ability of Havens to remain financially viable.

In their submission, Mind Australia reported the Haven model to be cost-effective due to the ability to share supports across a greater number of participants, delivered by a single provider. They reported the average annual Assistance with Daily Living (ADL) support budget for participants in a Haven with standard intensity needs was $119,000. By comparison, the average annual ADL budget for all SIL participants was $296,700 in 2022-23.[1291]

As of October 2023, there were six Havens across Victoria, offering 96 individual residences. A further eight sites are under development, which will offer 124 residences. The Haven Foundation has advised that they have secured additional funding provided as part of the Victorian Government's "Big Housing Build" to develop further sites. The model is also expanding nationally, with funding secured to develop Havens in New South Wales and South Australia.

Similar models to Haven exist. We heard from United for Care about its "vertical village" model in New South Wales, where participants have their own private apartments in sites close to amenity with on-site shared support.[1292]

There are also other examples of innovative approaches to accommodation. In Tasmania, the Supported Affordable Accommodation Trust (SAA Trust) has developed 11 sites, with each offering either three two-bedroom units or six one-bedroom units (or a combination) with on-site shared

support delivered to all participants by a single provider.[1293] By featuring a modular design, participants with differing needs can be more effectively supported, whilst still sharing supports.[1294]

SAA Trust advised that construction costs are minimised through use of an easily replicable template design, with unit modules built in an off-site warehouse, and the houses are very energy efficient, keeping utility costs for residents as low as possible.[1295] SAA Trust retains ownership of the finished property, which is leased to the on-site living support provider who sub-leases to the residents at affordable rates. To-date, properties have been financed by a mixture of government grants, private investment and loans.[1296]

In North Queensland, Synapse worked with the local community to develop the Cairns Community Living Initiative (CLI), the first purpose-built housing complex for First Nations people with complex disability. The CLI consists of four duplexes, and eight sole-occupancy homes. The design of the built form was informed by community and Traditional Owners and includes areas that promote external living, cooking, yarning circles and layering of public and private spaces. Key features of the CLI include a culturally safe physical environment and culturally informed service delivery.[1297]

Another innovative approach is the '10+1' accommodation model pioneered by Summer Foundation. This model involves 10 SDA apartments in larger residential complexes located near accessible transport and other community amenities and an additional apartment that provides a base for support workers. The model ensures support is available 24 hours a day, 7 days a week if the need arises. In 2017, Summer Housing was established to replicate and scale up the '10+1' model. It has delivered in excess of 400 apartments across all states and territories except Tasmania and the Northern Territory.[1298] Our understanding, however, is that in most 10+1 SDA models there is limited sharing of daily living supports, with only overnight or ad-hoc additional supports shared amongst the resident group.[1299]

Alongside innovation, the application of best practice is crucial to delivering quality housing and living supports. For example, there is a large body of evidence that current best practice for delivering quality support to people with intellectual disability is through an 'Active Support' model (note that this is different from 'active overnight support').[1300] Active Support describes person-centred practice and individualised ways of supporting people with intellectual disability to maximise their involvement in daily activities.[1301] Many submissions have expressed support for greater use and training on Active Support.[1302]

Active Support practice involves two components: how staff provide support, and how they interact with the people they support.[1303] Good practice Active Support includes the following elements:

- Every Moment has Potential for people to be engaged – wherever and whenever people and staff interact.
- Graded Assistance to Ensure Success – there is no hierarchy of different types of assistance, the focus is on finding the right type of assistance for each individual.
- Maximising Choice and Control – respecting preferences and choices of the person being supported.

- Little and Often – some people need frequent opportunities to experience new things, and short periods of engagement rather than lengthy continuous periods.[1304]

There is strong evidence that staff using Active Support approaches positively influences the quality of life outcomes for people with intellectual disability across the domains of personal development, emotional wellbeing, autonomy, interpersonal relationships, and social inclusion.[1305]

Frontline Practice Leadership is also recognised as an evidence-based best practice model of leadership for frontline supervisors overseeing support workers, which can improve service delivery and the quality of Active Support practice.[1306] It involves:

- Focusing staff attention on the overall quality of life of the people supported.
- Allocating and organising staff to provide the support people need, when they need it, to maximise their quality of life.
- Observing, giving feedback, coaching and modelling to shape up the quality of staff support.
- Supervising the practice of each staff member individually.
- Facilitating teamwork and team meetings to share information, and ensure consistency and collaboration.[1307]

Research shows that high quality Active Support has similar costs to low quality support, and can reduce challenging behaviour and thus reduce the need for higher intensity support.[1308] It can also result in participants experiencing increased engagement in meaningful activities and social interactions, as well as improvements in skills, personal development and adaptive behaviour.[1309]

But preliminary findings from a longitudinal study into Active Support and Practice Leadership conducted by the Living with Disability Research Centre found that the quality of Active Support and strength of Frontline Practice Leadership decreased between 2018 and 2022.[1310]

> *"The impact of the lower quality of Active Support is that increasingly people with intellectual disabilities live in a 'hotel model' of supported accommodation, where staff are often unclear about their role, and staff do most of the tasks associated with daily living for people and provide very little support for people to exercise choice or be engaged in meaningful activity or social interaction. This means that people living in accommodation services spend a significant of proportion of their time disengaged – doing nothing." – The Living with Disability Research Centre, La Trobe University[1311]*

The NDIS Commission's Own Motion Inquiry into Aspects of Supported Accommodation recognised the value of Active Support and Frontline Practice Leadership as elements of a best practice framework for supported accommodation.[1312] The Own Motion Inquiry proposed the development of new Practice Standards and Quality Indicators that apply specifically to supported accommodation settings and include requirements for Active Support and Frontline Practice Leadership.[1313] We discuss the development of new Practice Standards further in Chapter 5, which examines how to promote and incentivise continuous quality improvement.

We also heard about the role of peer support workers in helping people with disability in SIL homes develop community connections.[1314] The Community Disability Alliance Hunter's

Community Connections Project focuses on building the capacity of staff and peer workers to support people with disability who have moved from Large Residential Centres to smaller SIL homes to build and develop community connections.[1315] Peer workers build relationships with their peers living in SIL homes and work collaboratively with the person's support workers and informal support networks to identify and address challenges facing the person to develop community connections.[1316]

The KeyRing model in the UK is another example of an innovative housing and support service model.[1317] KeyRing is a flexible, low cost service based on a collective, sharing resource model.[1318] KeyRing centres on support networks that allow people to live in their own place in an ordinary community and receive support from other network members that live close. These support networks help people build community connections and independent living skills.[1319] In 2018, an independent study of the UK KeyRing service model demonstrated significant service outcomes and financial benefits of a typical KeyRing network.[1320] The KeyRing model has been trialled in Australia,[1321] and a 2014 Victorian inquiry into social inclusion highlighted the KeyRing model as a cost-effective initiative and an example of the way in which flexible housing can help people with disability achieve independent living.[1322]

4.1.3. A range of barriers limit the uptake of more diverse and innovative housing and living options

Participants and providers alike face barriers to the uptake of more diverse and innovative housing and livings support models.

Barriers for participants

As highlighted in section 3.22, participants and their families face a range of obstacles in exploring different housing and living support options, including:

- Limited structured support provided to families to build the capacity and independent living skills of their child during their formative years.
- Insufficient time to plan for a move to independent living, with some forced to move at a time of crisis, such as when a parent can suddenly no longer sustain high levels of informal support.
- Inadequate access to independent, specialist advice and support to explore and evaluate different housing and living options, including difficulty finding information on successful outcomes for others accessing particular types of arrangements.
- An inability to try different arrangements before finding a solution that works.

We also heard of specific barriers accessing funding for ILO, associated with a lack of knowledge and understanding of what ILO options are, a lack of information from planners and LACs about evidence requirements, a lack of access to informal supports, low rates of approval for ILO – Exploration and Design funding, and difficultly finding a Support Coordinator who can assist in implementing ILO funding.[1323] The announced closure of Western Australia's Individualised Services (WAiS), a strong supporter of ILOs, is likely to exacerbate this difficulty.[1324]

These barriers are magnified by the broader housing availability and affordability challenges facing all Australians. For participants who have limited access to resources (including informal support, finances and broader reserves of social capital), many enter the most common housing and living arrangement in the support landscape – SIL delivered in a group home.

Barriers for providers

Providers also face challenges in developing and sustaining new and innovative housing and living support models.

We have heard that many providers are reticent to explore ILO for a number of reasons. There is a lack of knowledge and understanding about ILO and the pathway is seen as complex.[1325] There are also unclear obligations relating to quality and safeguarding, industrial relations and taxation law.[1326] Under ILO, a service provider assists a participant to establish an ILO arrangement. They also have responsibility for monitoring the arrangement. However, the service provider is not involved in the delivery of day-to-day living supports, with these instead being delivered by the primary support. Nevertheless, an ILO provider still has quality and safeguarding obligations under the *National Disability Insurance Scheme Act 2013* (NDIS Act). We have heard this can present a great deal of uncertainty as to their accountability for risk and duty of care, which is a barrier to further adoption.

The individual delivering primary supports in an ILO arrangement is also expected to provide significant levels of informal support. We have heard that this approach can make it difficult to find suitable hosts and housemates and there can be high turnover, making the ILO model difficult to sustain and scale. In interviews and focus groups conducted as part of the NDIA's recent *Having a Go* report, participants and their families reported struggling to find host families or housemates even with the support of an ILO provider.[1327] In addition to providing informal support, some hosts and housemates may receive a notional weekly stipend paid out of the ILO funding package, or receive discounted rent in exchange for the support they provide. This mix of paid and unpaid labour can create challenges for both providers and participants in navigating both industrial relations and taxation law.

Leaving ILO aside, providers have highlighted a range of other practical barriers to the delivery of more innovative supports. For SIL supports delivered to a shared household, providers have highlighted how rigid individualisation of funding linked to direct hours of support can create perverse outcomes (see section 4.1.6).

There are further issues with unaligned plan reviews for participants within the same household, which creates additional administrative and workforce rostering complexity for service providers, contributing to higher overhead costs including additional administrative staff to deal with rostering changes. In a survey of more than 1,600 disability support workers conducted by the Health Services Union (HSU), only 13.9 per cent agreed that plan reviews were well coordinated.[1328]

> *"NDIS plans within the same provider need synchronised review dates so that funding from individual plans fully covers shared costs and compensates workers for all hours worked." – Health Services Union[1329]*

"NDIS planning cycles do not align, creating regular disruption for households and negatively impacting one another as their co-resident's needs change. It is also inefficient, for example, providers report on having five different Occupational Therapy (OT) assessments to assess the same bathroom. Support plans, including specialist behaviour support plans are developed by different professionals, in different styles. They don't consider the needs of the wider household, or relationship dynamics, rendering them largely ineffective with, in some cases what is advised in one client's plan may undermine another co-resident's plan." – Anonymous[1330]

More broadly, with NDIS-funding mechanisms focused on outputs, in the form of direct support hours, rather than outcomes such as developing independence or improving quality of life, there is little incentive for providers to move away from the status quo and innovate.[1331]

"There are not sufficient margins in the current hourly rates to fund innovation. The Benevolent Society does not have an alternative source of lead investment to create projects such as this. Funding innovation through hourly rates creates an incentive for providers to capture the benefits of innovation within their own organisations, rather than share improvements broadly with the market for the benefit of all people with disability. This may work against higher impact innovation projects that reach across multiple providers." – Benevolent Society[1332]

The issue of fee-for-service payments and their role in incentivising the quantity of supports delivered, rather than the value of those supports to participants, is discussed in more detail in chapter 4.

We have also heard that the almost constant reforms of the last decade have diverted providers from investing time and focus in improving their service models — particularly for providers supporting significant numbers of participants transitioned from previous disability service systems.[1333]

Providers also have little guidance on the nature of alternatives and how these might be funded, including limited demonstration of alternatives.[1334] The Home and Living demonstration projects currently funded by the NDIA focus on funding flexibility for SIL arrangements, but publicly available details about the projects funded, and any findings, is at this stage limited.[1335] There is also very little information as to the nature of successful non-SIL arrangements, including factors such as level of need, type of arrangement, costs, outcomes and processes for monitoring outcomes.

4.1.4. Overcoming these barriers requires multi-faceted change

There is no quick fix for overcoming these barriers and enabling the housing and living support market to flourish with diversity and innovation. It will require multi-faceted change across a range of areas, as outlined in the following sections, underpinned by effective market stewardship and complemented by a new budget setting approach.

There is also no single model of housing and living supports that needs to be identified and scaled up. We envisage participants, within the bounds of their assessed housing and living budget, having the ability to explore, trial and choose their living arrangements through a selection of options similar to the matrix below (Figure 95).

Participants have the right to be informed about and choose housing and living arrangements that mix and match dwelling type, household size and support models that best suit them. The suitability of different arrangements will vary for different individuals depending on their level need, access to informal supports and family involvement.

Figure 95: Possible features of different housing and living support models

| Dwelling type | Living with informal supporter | | Single residency | |
| | Multiple residents | | Single residency, co-located | |

| Number of participants | 1 | 2 | 3 | 4 | 5+ |

| Delivery mode (daily living supports) | Drop-in | | Onsite | |

| Sharing of supports (daily living supports) | None | Overnight/Ad-Hoc | Full Sharing |

| Best suited for participants with | Physical or sensory disability | Episodic psychosocial disability | Intellectual disability |

| Level of supervision with activities of daily living | Very Low | Low | Medium | High | Very High |

| Level of informal supports | None | Low | Medium | High | Primary Carer |

| Level of family involvement | None | Low | Medium | High | Very High |

| Typical costs | Low | Low/Medium | Medium | Medium/High | High |

For example, a participant with lower intensity support needs (such as someone with moderate intellectual disability and no physical impairment) might be supported by a housemate delivering day-to-day informal supports in a private rental, with supplementary drop-in supports (akin to the way a housemate ILO arrangement is designed to operate). This could be funded flexibly out of their core support budget, without necessarily needing a housing and living budget designed for those with 24/7 living support needs. However, given the known challenges of sustaining ILO-like arrangements (particularly finding suitable long-term housemates) this arrangement may only be suitable for those with strong informal support networks who can help maintain the arrangement, including finding replacement housemates as turnover inevitably occurs.

Participants with more intense, but fluctuating or episodic, support needs who require disability support workers to be on-hand, but not necessarily delivering constant high-levels of active support and/or supervision, might be best supported in a clustered housing arrangement. They may have their own single-resident dwelling, co-located with others to share daily living supports.

This type of model can be particularly suited to participants with psychosocial disability, as demonstrated by the Haven Foundation model. It might also suit participants who can self-direct their support, for example, those with high physical support needs who can use technology to call for additional ad-hoc assistance from an on-site shared support provider outside of their usual schedule of supports.

For those with the most complex support needs, where having near-immediate access to a support worker is essential for their safety (e.g. responding to known behaviours of concern and/or complex disability-related health conditions), a well-matched 3-resident share house arrangement with overnight assistance might be the most appropriate model.

This list of examples is by no means exhaustive, nor is it intended to be prescriptive. As outlined in section 2.4, our vision is that, as the sector develops over time, all participants find housing and living supports that are safe, provide choice and agency, are connected to community and offer a place to call home, and that these features are present irrespective of the precise model, and whether the home is shared or not.

> *"Contemporary options can include some levels of shared care with higher levels of privacy and independence." – Anonymous*[1336]

4.1.5. Better data is crucial

An essential enabler of diversity and innovation is good data. Knowing where participants live, the arrangements and types of dwellings they live in and whom they live with is pivotal to understanding how they are supported by the scheme and analysing what works for people in different situations over time. Unfortunately, this is currently not the case. At 30 September 2022, the living situation of more than 300,000 participants was not known. While not all of these participants would be accessing housing and living supports, information on the living arrangements of participants funded for SIL and/or SDA is also poor (see section 2.3).[1337]

Many submissions called for the collection of more data and analysis.[1338] For example, the Community Housing Industry Association (CHIA) suggested that the NDIA set up an appropriately constituted advisory group to oversee the collection, analysis and publication of data about housing needs, and that the NDIA and/or DSS should commission research to demonstrate the benefits (including savings on support) that would be achieved through providing suitable housing.[1339] In its *Reimagining Shared Housing and Living* report, the Summer Foundation called for the collection and dissemination of data for people who currently live in group homes to improve the sector-wide understanding of that group.[1340]

Without better data and information, families and participants and their Navigators, as well as providers and the NDIA, will not be able to evaluate different housing and living options. Providers will not be pressured through competition and informed consumers for change, and traditional solutions – often inconsistent with best-practice support and the concept of home – will continue to dominate. Effective monitoring of performance of providers will also be difficult to achieve.

Key data and information required includes:

- Data on where participants live and the characteristics of their living arrangements, including shared living arrangements, and changes over time.
- Data on caring arrangements, including the age of primary carers, to help identify those who should be prioritised for reassessment.
- Data on the quality of participants' living arrangements.
- Compliance and performance of housing and living support providers against all required standards.

Better analysis of the data is also required. Improved evaluations of what and how living supports are being delivered could provide a feedback loop into budget setting decisions so that the NDIA can alter provisional budgets as the sector innovates and the cost of new, best practice models becomes clearer.

> *"At present data collected by the NDIA is not easily available for public analysis. The NDIA is uniquely placed to collect data in comparison to other market participants. In comparison, if a provider were to determine a reduction in support costs arising from independent living, it would be required to conduct detailed interviews, obtain consent to access plan information and undertake manual data re-entry to create a dataset which already exists. We believe that the NDIA should develop a visible internal capability that provides analysis of support models and practices market analysis, discussion and debate as to their effectiveness. Informed by this crowdsourced rigour the NDIA could publish a position paper which is then adopted as evidence based policy with a comprehensive consultation on its merits." – Anonymous[1341]*

The development of a microsimulation model to simulate the responses of participants and providers to changes in housing and living arrangements would also enable better analysis and evaluation. Microsimulation models simulate individual-level decisions and the interaction of decisions amongst individuals. They are commonly used to assess the impact of government policy

changes and are particularly useful where there is a wide variety in decision makers, and complex policy changes are likely to impact these decision makers in different ways. They can incorporate information from large data sets that reflect the differences found in the population and generate detailed results to facilitate analysis of how a policy might affect particular groups.[1342]

Development of a microsimulation model would build capability to analyse and publish details on:

- The cost and suitability of different alternative housing and living support models.
- Forward-looking market data, including projections of the level and type of committed and potential future demand for housing and living supports by age and disability type and location.

In line with this, National Disability Services called for better use of data to support a deeper understanding of the types of models of housing and living, and the relative costs and benefits of these models (for example individual living options).[1343]

Enhanced data and analysis should be complemented by better measurement of outcomes and performance, as outlined in Recommendation 23. We note the development of the Disability Housing Outcomes Framework by Social Ventures Australia to measure housing outcomes and assess what works.[1344] This could form the basis for further work in this area.

4.1.6. More effective market stewardship is also needed

Data and information alone is not enough. Stronger and more active market stewardship is also needed to support participants as informed consumers to drive market change, and support providers to become more efficient, innovative and responsive to participants. This will, over time, enable the sector to evolve to deliver a variety of options for participants to choose from, that have all of the features set out in the vision outlined in section 2.4.

As outlined in chapter 4, there are many aspects to market stewardship. Each of these are touched on in this section as it relates to the market for housing and living supports, but brings together material about aspects of market stewardship more generally from across the Review.

Market facilitation

Market facilitation is about improving connections between participants and providers through engagement and information sharing (see chapter 4). The collection and publication of detailed, disaggregated, tailored and forward-looking market data (as outlined in section 4.1.5) is one essential element of this.

Another key element is the diffusion of innovation and best practice — the communication and adoption of new ways of doing things. As outlined above, there are already pockets of innovation occurring (see section 4.1.2), and we expect our package of recommendations to accelerate that process by:

- Helping participants understand and choose models that best suit them

- Reforms to SDA to ensure people have access to the infrastructure that facilitates the effective delivery of best-practice living supports (see section 4.22)
- Using enrolment payments (with testing outcome payments) for shared living supports where the provider can benefit from investing in better models of delivery.

Navigators will play a key role in knowledge translation. They will be experts in what housing and living options are available in the market, which providers are at the forefront of innovation and what is best suited to the needs of particular participants. The dedicated quality function proposed for the new National Disability Supports Quality and Safeguards Commission (see Recommendation 12) will also be an essential component, as it will:

- Incorporate outreach to providers to monitor performance, advise on quality improvement through provider communities of practice, and gather intelligence about innovation in support design and delivery.
- Create an online 'Centre of Excellence' resource library, including research, guidance and advice on good practice models of support delivery that providers could adopt in different contexts. This should include collaboration with the new Disability Research and Evaluation Fund (see Action 23.3).
- Facilitate industry collaboration forums and provider communities of practice to set expectations and share information about good practice.

The proposed Disability Research and Evaluation Fund (see Action 23.3) will also play a part through its coordination and funding of research and independent evaluation activities, and in its role in supporting and promoting awareness and application of best practice evidence by policy makers and service providers. In its submission to this review, CHIA called for something similar:

> *"A national research centre on contemporary housing for people with disability should be established to measure outcomes, share technology and design innovations and promote best practice"*[1345]

Another aspect of market facilitation is effective matching of participants sharing supports, whether that is under the one roof or in individualised, but co-located, dwellings. Better resident matching will be facilitated by:

- More flexibility in how housing and living budgets are used.
- Independent Housing and Living Navigators with specialist expertise in the range of local housing and living supports (see Action 8.2).
- Arrangements to trial housing and living options (see Action 8.3).
- Vacancy payments for living support providers and aligned budget reassessments for participants sharing living supports (see below) which remove incentives for providers to place a participant irrespective of their compatibility with the existing resident group.
- Reducing the bedroom count of ageing SDA dwellings to no more than three residents, so providers are not financially compelled to keep placing residents into this ageing stock (see Action 9.9).

Market settings – pricing and payments approaches

Market settings include pricing and payment approaches, and market access settings. We have heard that the current approach to pricing and payments has led to poor quality in the delivery of living supports on a number of fronts.

We have heard that the fee-for-service pricing approach does not adequately capture and compensate SIL providers for the breadth of supports or duty of care they need to provide to deliver good outcomes for participants.[1346] We have also heard that it does not adequately capture costs that extend beyond hours of face-to-face service delivery, particularly for participants with complex needs (for example, case management and engagement with other universal service systems such as the health system).[1347] While these supports are intended to be delivered by Support Coordinators or other intermediaries, this does not always occur. These issues can create perverse incentives for providers to seek increases in the volume of direct support hours to offset unfunded indirect support costs.

Regular changes to SIL pricing and payment approaches suggest some difficulty reconciling the shared and recurrent nature of 24/7 living supports with fully individualised fee-for-service payment approaches. As shown in Box 45, since full-scheme transition commenced on 1 July 2016, there have been significant policy changes to SIL pricing and payment approaches over the last several years.

> *"There has been frequent revision of models of costing and claiming for SIL supports which has created a lack of clarity. Policies, funding, planning and implementation need to ensure the adequacy of funding to support participants with complex needs and address issues related to shared supports, including the impact of vacancies on the shared components of support of remaining residents." – National Disability Services[1348]*

Box 45: Summary of major changes to SIL pricing and payment approaches

Price Guides published by the NDIA from 1 July 2016 to 30 June 2020 appeared to explicitly recognise that as a shared support, SIL funding needed to account for both an individual's support needs as well as how collective supports were shared among a resident group. The NDIA's *2019-20 Price Guide* stated that the purpose of SIL quotes was to identify both the individual supports available to a participant as well as "the typical roster of supports that is shared between participants to maximise the efficient use of resources" and "what supports are available to all residents to ensure the smooth operation and running of the household".[1349] During this period, SIL was a quotable support and not subject to price caps.

From 1 July 2020, the NDIA shifted SIL pricing from a household quoting process to a completely individualised and price capped SIL budget. SIL budgets were set by the NDIA using an internal calculator based on a range of inputs including an individual participant's assessed ratio of support, support intensity and overnight support needs. SIL ceased to be a stated support and could be used flexibly within an individual participant's core support

budget. This change better recognised the needs of each participant, but created a range of service delivery challenges for providers – including unnecessary administrative costs and complexity when delivering a set of relatively stable recurrent supports, and difficulties funding unplanned support needs. Two subsequent changes attempted to deal with some of these issues.

The first was the introduction of 'Irregular SIL Supports' only five months after the 1 July 2020 introduction of capped SIL prices. This enabled providers to claim for support costs when a participant required support outside of their scheduled SIL supports, for example, if a participant became unwell and could not attend a scheduled community support requiring support at home for the duration of the absence.

Later, the NDIA introduced optional weekly claiming for SIL supports in its 19 April 2022 Price Guide.[1350] This gave providers the option of bundling up all the ADL supports delivered to participants accessing SIL in a typical week, instead of claiming for individual hourly price caps for different times of the day and days of the week. SIL providers could choose to either claim for the weekly support or maintain hourly claiming, however they could only choose one method.

We have also heard that the current individualised funding approach does not always align with service delivery in shared living settings. We received a number of submissions which reiterated the interconnected nature of shared living supports and highlighted how individualisation, when applied rigidly and exclusively, can undermine quality:

> "A participant does not necessarily live independently from those who share their home and in order to acknowledge each participants rights, and choices, participants should have the opportunity to share or coordinate their supports as part of that household. The individualised way in which shared support is currently funded through the NDIS, is deeply flawed and undermines the concept of an ordinary life. It does not recognise the unique and interconnected needs that people living in shared arrangements have and the provider who requires a reliable and stable income stream to ensure services are maintained and not interrupted. NDIS planning cycles do not align, creating regular disruption for households and negatively impacting one another as their co-resident's needs change." – Anonymous[1351]

> "Using an individualised funding model for a shared service in SIL settings also masks systemic service delivery issues including cross subsidisation between participants, overfunding for contingencies, and fair allocation of costs for participants sharing their supports." – Young People in Nursing Homes National Alliance[1352]

> "The NDIS' individualised pricing structure works poorly in shared living arrangements. It prevents providers from investing in shared costs to support safety, as spending must be tied to an individual's plan. It makes funding for supported living unpredictable, as one participant's withdrawal from a provider can undermine the

viability of supports of other residents they live with. It leads to unstable rosters that impact the ability to recruit and retain staff, and as a result, staff vacancy rates have never been higher." – Health Services Union[1353]

One example of this is unaligned plan reviews for participants sharing supports in a single household, outlined in section 4.1.3. Another example is the limited allowance for funding vacancies in shared living arrangements.

Currently, a participant can voluntarily exit a shared SIL arrangement with 14 days' notice, however a SIL provider cannot claim vacancy payments for any period, despite losing the exiting participant's portion of the shared support costs. We have heard that this can lead to an overall reduction in the amount of support offered to the remaining participants for the duration of the vacancy and create perverse incentives for providers to fill the vacancy quickly, without regard to the preferences of the existing residents.

"Filling a vacancy successfully can take some time and organisations work through a carefully considered framework which can often take months." – Anonymous[1354]

In limited circumstances, the NDIA provides 'SIL unplanned exit payments' for a maximum of 28 days but only for when a participant in the shared arrangement dies or leaves due to "an irretrievable breakdown of supports/relationship which requires an immediate exit due to the participant's personal health and safety, or that of others, is critically compromised".[1355] By comparison, the NDIA funds SDA vacancies irrespective of whether a participant dies, leaves voluntarily or leaves involuntarily.[1356] Vacancy payments can be claimed for a maximum of 90 days for SDA dwellings enrolled to house either 4 or 5 residents, and 60 days for those enrolled to house either 2 or 3 residents.[1357] These SDA vacancy payments are additional to base prices for New Build SDA dwellings, which have an inbuilt vacancy assumption of between 7.75 per cent and 13 per cent.[1358] There is no comparable vacancy assumption included in SIL price caps.

We believe that exclusively individualised approaches – planning, funding and payments – are misaligned with the delivery of shared living supports. This remains the case whether participants live together under one roof (for example, in a share house or group home) or in settings where participants live alone (or with partners and/or children), but are co-located with other participants and share living supports.

To overcome this problem, we recommend introducing an integrated service delivery approach for participants sharing living supports. This approach would have three key features.

Firstly, it would draw together an appropriate, but limited, set of supports to better coordinate services for participants who are sharing living supports. This could include supports such as:

- Direct face-to-face living supports such as personal care, mealtime support and related supports).
- Access to community and other mainstream services (for example, attending appointments and shopping for household essentials), including transport costs, and coordination of related supports (like making a doctor appointment or other appointments).

- Contingency supports that cover periods when a participant is unwell. This could include:

  - Coordination with other support workers and service providers when the participant cannot attend a separately organised activity outside the home, ensuring that replacement support is available at home for the length of the unplanned absence.

  - Additional care at home (whether it is during the day or overnight) during the period of illness (noting that if the period of illness is protracted, this might trigger a change of circumstances budget review).

- Vacancy payments to ensure continuity of supports for the remaining residents immediately following a departure, and to facilitate good co-resident compatibility.

  - These payments should align with those for SDA.

  - The adequacy of these vacancy payments should be carefully monitored based on feedback from Housing and Living Navigators.

It is important to note that bundling supports together into a single payment does not preclude individualised and person-centred practice, or lock participants into their current arrangements. Indeed, it is possible that greater stability of funding can reduce workforce casualisation and support the growth of a more stable workforce that is familiar with the needs and preferences of the people they support.

Additionally, participant budgets would still be based on individuals' needs. Participants funded for shared living supports who need 1:1 support for particular tasks, such as support with personal care, would have these needs accommodated in their individualised budget. There would also be a range of individualised supports that exist outside a participant's housing and living budget, including capacity building and social, civic and community participation – which participants can use flexibly.

The second key element of the integrated service delivery approach is the introduction of pooled funding arrangements for shared supports. Funding for 24/7 living supports for participants sharing supports would be a stated item in each participant's housing and living budget. Once a participant has chosen their preferred living support provider, their living support budget would be pooled with the other participants they are sharing with to cover the set of integrated supports. Payments for the chosen provider would move away from fragmented fee-for-service approaches to an enrolment payment that rewards providers for building the capacity of participants and strengthens incentives for providers to invest in the capabilities of participants over the enrolment period.

The enrolment payment should cover the defined bundle of shared living supports and could incorporate a small outcome payment. Initially, the outcome payment could be a more simple measure of the participant's satisfaction with their living supports provider. Some participants could complete this with the support of their Navigator or informal supporters. Over time, the outcome-based component should be further designed, evaluated and updated with participants and providers (see Action 11.1).

Under this approach, the provider's accountability should be clear in the quality and safeguarding arrangements, and should be enforced, in line with the broader regulatory approach outlined in Recommendation 17. Expectations around service standards and supports should be embedded in service agreements between the participant group and their provider. Shared Support Facilitators (see Action 8.4) would have an important role to play in supporting participants to exercise joint choice over their chosen provider, as well as assisting them to set up a service agreement and monitor and check-in with participants over the enrolment period to ensure the agreed service standards are being met.

The third element of the integrated service delivery approach involves aligning regular budget reassessments for participants sharing supports. This would better enable pooling of funding to deliver shared living supports, and reduce administrative complexity for providers. When there is a significant change in the circumstance to those sharing that changes the actual cost of delivering services to them (such as someone leaving/joining the arrangement) then the actual cost for the individuals sharing supports should be adjusted in their budget so as to ensure that shared arrangements remain effective. This should still fall within each individual's provisional budget and so as to not require a budget reassessment.

This new approach to delivering 24/7 living supports should lead to fewer disruptions, clarify expectations, and strengthen the incentives for providers to focus on delivering quality support and investing in shared costs that support safety and promote good outcomes for participants.

One criticism of such an approach, however, is that it will stifle choice and control, as each participant sharing supports must use the same living support provider. However, the reality is that participants currently sharing supports already lack that choice. While the 1 July 2020 changes to SIL pricing and payment approaches described in Box 45 enabled individual participants funded for SIL supports to choose different service providers, this does not happen in practice:

> *"The way in which SIL is funded would suggest that although it is technically possible for NDIS participants living in a group home to each choose different providers, in practice this is not what occurs. Certainly there were no examples of this kind observed through the Inquiry." – NDIS Commission*[1359]

There are significant administrative and practical barriers to splitting funding between different providers. For example, in an arrangement where three participants are funded on the basis of an average 1:3 support ratio, if all three participants chose different providers to deliver their 1:3 shared support, a single worker would need to have an employment relationship with three different support providers (each contributing one-third of their wage). Alternatively, three different workers from three different providers would be employed, but each provider would only be funded for one-third of an hour of support. Different providers can also lead to arguments about provider responsibilities for shared spaces.

> *"The NDIS should review the use and promotion of multiple external providers of specialist support to people with intellectual disabilities in supported accommodation. This will encourage accommodation support providers to focus on the effectiveness of*

the enabling everyday Active Support they provide, ensure greater consistency of support and optimise use of the knowledge, skills and continuous presence of accommodation support staff. Reducing external providers will assist in creating more predictable and consistent support and reduce fragmentation, duplication and waste of resources on coordination with external professionals." – The Living with Disability Research Centre, La Trobe University[1360]

Having the one provider deliver an integrated set of supports can have many benefits. The NDIS Commission pointed to broader benefits for participants funded for shared support accessing a single provider, including collective agreement over the support workers entering the home and greater predictability and stability over how many will be present at any point in time. If each participant in a shared living arrangement chose their own support provider, there would be no or limited visibility of the support workers each individual participant chose to enter the home. Multiple concurrent and overlapping support rosters would also be required, leading to more frequent adjustments. For some participants, regular changes to established routines can be destabilising and contribute to escalating behaviours of concern. Further, in many shared settings it is essential that support workers are familiar with the support needs and preferences of all residents, which would be less likely to occur when shared support was fragmented across multiple service providers and support workers.[1361]

Nevertheless, we acknowledge that this approach to pooling funding represents a significant shift from current arrangements. It is therefore crucial that the details of this approach are designed together with participants and the sector, in particular clearly defining what defined mix of supports are appropriate to bring together under this arrangement.

Quality and safeguarding oversight

Effective regulation is particularly important to ensure high-quality supports and safeguard the rights of people with disability (see Chapter 5). The Review has recommended a new graduated, risk-proportionate model of regulation for the whole provider market that will strike the right balance between regulatory requirements and oversight that prevent harm without imposing disproportionate burden on the market (see Recommendation 17).

This model should apply across the diverse range of housing and living support settings, whether a traditional group home, a share house or clustered housing. However, the model will be applied differently depending on the risk of a provider's activities and operations. This will likely mean:

- Mandatory Advanced Registration and in-depth observational auditing of providers delivering the highest-risk housing and living supports, such as 24/7 living supports – as well as mandatory registration or enrolment of all other housing and living supports (proportionate to risk) (see Action 17.1).
- New or amended support-specific Practice Standards for different types of housing and living supports, including a new support-specific Practice Standard for 24/7 living supports (see Action 17.1).

- More proactive regulatory posture – for example, better use of regulatory intelligence, use of provider outreach to build provider capacity and monitor performance and compliance, and active use of the full range of compliance levers where needed (see Recommendations 17 and 19).

This risk-proportionate model of regulation (see Recommendation 17), supported by other recommendations, including Navigators (see Recommendation 4) and the shared support facilitation function (see Action 8.4), are designed to ensure that the range of housing and living supports available to participants are safe and high-quality.

4.1.7. Action & Implementation Details

Action 9.1: The National Disability Insurance Agency, in collaboration with the new National Disability Supports Quality and Safeguards Commission, should invest in the collection and dissemination of housing and living data and analysis

Detailed, disaggregated and tailored data, analysis and information on housing and living supports should be collected and disseminated. A more robust evidence base should inform better diversity and innovation in housing and living supports offerings and underpin more effective market stewardship arrangements.

Implementation detail:

- Data and information should be mapped to the International Classification of Functioning, Disability and Health (ICF) and should include:

  - Data on where participants live and the characteristics of their living arrangements, including shared living arrangements, and changes over time.

  - Data on the quality of participants' living arrangements.

  - Compliance and performance of housing and living providers against all required standards.

- Analysis should be supported by the development of a microsimulation model to simulate the responses of participants and providers to changes in housing and living arrangements. Microsimulation models are commonly used to assess the impact of policy changes, and are particularly useful where there are complex changes that are likely to impact different groups in different ways. This should build the capability of the NDIA to analyse and publish details on the:

  - Cost and suitability of alternative housing and living support models.

  - Forward-looking market data, including projections of the level and type of committed and potential future demand for housing and living supports by age and disability type and location.

- Improved data and analytical capabilities should underpin and enable more effective stewardship of the market through:

  - Better translation of knowledge and diffusion of best practice and innovation through the Housing and Living Navigator (see Action 8.2), the dedicated quality function established within the new National Disability Supports Quality and Safeguards Commission (see Action 12.1) and the centralised online platform (see Action 10.1).

  - Changes that support participants to more flexibly exercise choice and control as informed consumers and link to a wider range of service options (see Actions 3.3, 3.5, 4.1, 5.3 and 8.2).

  - Enhanced connections between participants and providers (see Action 10.2).

  - The introduction of an integrated service delivery and funding approach to better enable and incentivise providers to deliver quality, best practice and innovate living supports in shared settings (see Action 9.2).

  - Appropriate quality and safeguarding oversight of the delivery of housing and living supports, including mandatory registration and auditing of providers delivering highest-risk housing and living supports (see Actions 17.1 and 12.2).

Action 9.2: The National Disability Insurance Agency should implement a new funding approach for participants sharing living supports to strengthen the focus on service quality and outcomes

The new funding approach should be designed with participants, families and the sector. The approach should outline a set or 'bundle' of shared supports that should be the responsibility of the living support provider and that would ensure the provider is adequately funded and held accountable for participant outcomes, in line with the broader quality and safeguarding arrangements (see Recommendation 17).

As part of this funding approach, participants' funding should be pooled to cover this 'bundle' of shared supports. To better enable pooling and to ensure adequate ongoing funding for shared supports, reviews should also be aligned for participants sharing supports and when there is a significant change in the circumstance to the group sharing, such as, one participant vacating the arrangement. Shared Support Facilitators (see Action 8.4) should work with participants to develop a service agreement with their chosen living support provider.

Shared living providers should be paid an enrolment payment, which in time could include an outcome-based payment, for the agreed period set out in the service agreement. The enrolment payment, together with regular check-in from the Shared Support Facilitator to ensure service expectations are being met, would reward providers for investing in building

the capabilities of participants and their connection to community that contribute to more open settings, improve natural safeguards and could reduce the need for formal supports. With greater certainty of demand, providers might also have more stable workforces who know and understand the needs of residents and invest more in active support and assistive technology.

Implementation detail:

- The NDIA should work with participants, their families and the sector to design the three key features of an integrated model for shared living supports.

  - The NDIA should define an appropriate set of shared living supports. This may include:

    o Direct living supports (that is, personal care, mealtime support and related supports) (note, not all of this will be shared, individuals sharing will still need 1:1 support for some tasks).

    o Transport/access to community and other mainstream services (for example, attending appointments and shopping) and coordination of related supports (like making a doctor appointment or other appointments).

    o Vacancy payments that align with those for SDA, to ensure continuity of supports and facilitate good co-resident compatibility. The adequacy of these vacancy payments should be carefully monitored based on feedback from Housing and Living Navigators.

  - The NDIA should introduce pooled funding arrangements for shared supports, to clarify expectations and improve incentives for providers to deliver quality supports. Under this approach:

    o Participants should have choice over their shared living support provider who is accountable for the outcomes achieved for participants. Providers' accountability should be clear in the quality and safeguarding arrangements and be enforced, in line with the broader regulatory approach outlined in Recommendation 17.

    o Payments for the chosen provider should move away from fragmented fee-for-service approaches to an enrolment payment that rewards providers for building the capacity of participants. The enrolment payment should cover the defined bundle of shared living supports and incorporate a small outcome payment. Initially, the outcome payment could be a simple measure of the participant's satisfaction with their living supports provider. Over time, the outcome-based component should be further designed, evaluated and updated with participants and providers (see Action 11.1).

    o Shared Support Facilitators (see Action 8.4) should assist participants to setup a service agreement and monitor and check-in with participants over the enrolment period to ensure the agreed service standards are being met. They

should also assist participants, where needed, to report on their satisfaction with their living supports provider.

- The NDIA should align budget reassessments for participants sharing supports. When there is a significant change in the circumstance that changes the actual cost of delivering services to the group sharing supports, such as someone leaving/joining the arrangement, this should be reflected in individual budgets (as long as the actual cost remains below each individual's provisional budget). This will better enable pooling of funding to deliver shared living supports, and ensure that household arrangements remain effective.

4.2. The SDA market is not delivering the right homes in the right locations

The SDA market is still maturing, but has achieved much to date, attracting a large amount of private investment and increasing the supply of specialist accommodation. Nevertheless, there is a mismatch in demand and supply, underutilisation of SDA funding and a lack of innovation in dwelling design.

These issues are largely due to poor market data, inconsistent and slow decision-making, ineffective price setting arrangements, and a lack of market stewardship. There remains a need for more active stewardship and engagement with SDA investors and providers to ensure timely responses to real demand, balanced with appropriate participant protections.

4.2.1. The SDA market is still maturing

The vision for SDA under the NDIS is for the scheme to support a sustainable SDA market that fosters choice and control, encourages innovation, provides options for participants, and ensures continuity of supply and financial sustainability for governments, participants and providers.[1362]

The 2018 Review of the *SDA Pricing and Payment Framework* by KPMG painted a picture of the SDA market as evolving and one that would require more than a decade to deliver on its potential of partnerships, innovation and diversity to meet the needs of those requiring specialist accommodation.[1363] It outlined short, medium and long term characteristics of the market, where in the long term there would be a diverse, mature and competitive marketplace with innovative models driven by consumer choice, desired levels, types and locations of housing supply, and a greater understanding of how funding is provided.

Seven years into that market development, there has been good progress against some of these elements such as increased supply, new types of market entrants, and market-led matching services.

The vision for SDA of bringing private sector investment to create purpose-built and contemporary housing stock has been partially fulfilled. By 2018, approximately $700m in private sector funds had

been earmarked for the sector.[1364] Expenditure to-date has created an asset class of New Build SDA valued at $2.5 billon, and major fund managers are willing to bring their expertise to drive scale, efficient and impact for the sector.[1365] This has reduced the need for governments to commit large sums of capital funding when there are equally pressing demands for investment social and affordable housing for many other groups of disadvantaged Australians.

Involvement of the professional private equity sector and institutional investment market brings stability to investment where there is a capacity to absorb returns over the longer term. This, in turn, creates reliability in availability of stock. It has also allowed specialist knowledge, both from the perspective of realistic investment returns and building design and management, to evolve.

However, there are a number of issues identified in this Review that continue to affect investment decisions:

- Market information is inconsistent. Information symmetry between participants, providers and the NDIA has not been achieved. For providers there is limited data on availability, demand and future projections by building type, design category and location that will be supported by the NDIA.[1366] At the same time there is limited information for participants to inform choice of providers, the category best suited to their needs and alternatives to SDA.[1367]
- Inconsistent and slow decision-making has distorted investment. Inconsistency and limited transparency of decision making relating to SDA funding approvals for participants has delayed and complicated investment decisions.[1368]
- Pricing has not been an effective market lever. Price has not been used effectively as a signal to the market to address demand gaps. Indeed, the 2018 Review of the *SDA Pricing and Payment Framework* found that providers and investors acknowledged that prices at the time had skewed investment interest towards particular design categories and dwelling types that was not informed by actual demand data, leading to an oversupply of some build types, in particular, single resident High Physical Support.[1369]
- A lack of market stewardship has limited innovation in design. There are limited mechanisms to capture outcomes, benefits and experiences of living in SDA, to inform ongoing evolution in design features or support models that are responsive to participant choice.

4.2.2. There is a mismatch in SDA demand and supply

As a result of the shortcomings outlined above, there remains a mismatch in SDA supply and demand. While 3,818 New Build SDA dwellings (totalling 6,940 places) have been developed and enrolled in the seven years since SDA was established as a funded support, there remains substantial unmet demand, including from those in ageing SDA seeking alternative, more contemporary, housing solutions.[1370]

New SDA builds have not necessarily been built in the right locations, nor to the design categories or dwelling types that participants have been funded for. At 30 June 2023 over half (57 per cent) of all enrolled New Build SDA dwellings could only house a single resident.[1371] However, this supply response does not align with SDA funding decisions made by the NDIA (Figure 96).

Figure 96: NDIA data on eligible SDA decisions for the past three financial years shows that fewer than 1 in 5 of eligible decisions were for single-residency SDA[1372]

Year	Total eligible SDA decisions	Percentage of eligible decisions for single-resident SDA
2020-21	3,686	15%
2021-22	7,550	12%
2022-23	10,143	16%

Supply has also been concentrated in the High Physical Support design category, with 60 per cent of all enrolled New Build SDA built to this standard at 30 June 2023.[1373] This trend extends to SDA in the development pipeline. At 30 June 2023, 4,075 places in unfinished/unenrolled SDA were for the High Physical Support design category. However, of participants seeking an SDA place only 1,600 had an identified need for this design category (Figure 97).

Figure 97: Number of unfinished/unenrolled SDA places and number of participants seeking an SDA place at 30 June 2023 by design category[1374]
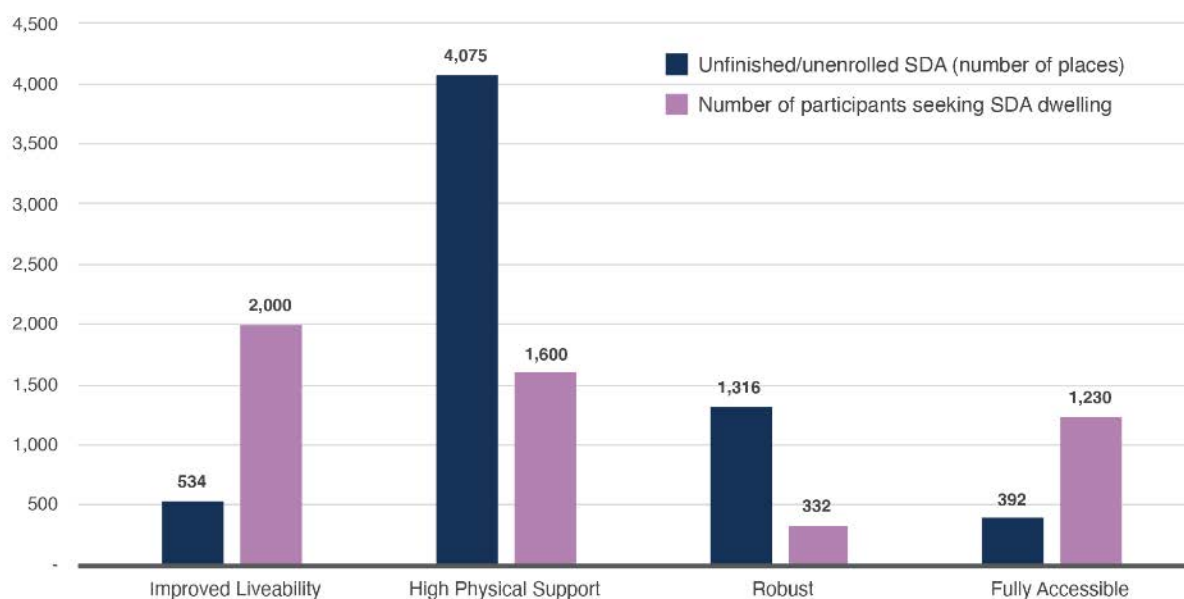
The consequences of this mismatch are revealed in the substantial number of participants with SDA funding in their plan, but not living in an SDA dwelling. At 30 June 2023, 23,092 participants had SDA funding in their plan, however only 13,971 (60 per cent) had evidence of living in an SDA dwelling.[1375] There were a further 1,300 participants living in an SDA dwelling, but did not have SDA funded in their plan.[1376]

Despite the substantial number of participants funded for SDA but not appearing to live in an SDA dwelling, we have heard that SDA vacancy rates are around 10 to 15 per cent, and sometimes higher.[1377] An SDA provider experience survey conducted by the Summer Foundation in June 2022 noted that out of the 1,281 New Build SDA places respondents had enrolled with the NDIA, almost a quarter were reported to be vacant.[1378]

Providers identified that the most challenging aspects of finding SDA tenants was finding participants with the right level of SDA in their plan, difficulty matching tenants' needs with the design level of dwellings, compatibility between tenants, and the location of supply and demand. We have also heard that finding tenants to fill vacancies can take between 6 and 12 months, whereas SDA vacancy payments are for between 60 and 90 days.[1379]

The NDIA maintains an SDA finder tool on its website which lists SDA vacancies that are voluntarily submitted by providers. On 14 September 2023 there were 1,448 vacancies listed, with almost half (48 per cent) in High Physical Support dwellings.[1380] By design category these vacancies were:

- High Physical Support: 698 vacancies across 391 dwellings
- Improved Liveability: 201 vacancies across 138 dwellings
- Basic: 200 vacancies across 152 dwellings
- Fully Accessible: 198 vacancies across 144 dwellings
- Robust: 139 vacancies across 90 dwellings
- Multi-Design Category: 12 vacancies across 5 dwellings.[1381]

A range of factors have contributed to high vacancy rates. It can take a year from the date a dwelling was enrolled to a participant moving in.[1382] Time delays in SDA funding approvals and decision making has been reported as another factor.[1383] Higher rates of vacancy related to higher mortality for participants accessing SDA have also been reported, particularly those eligible for High Physical Support, given a higher likelihood of degenerative illnesses and multiple disabilities.[1384]

These vacancies impact on confidence for future investments in SDA, as providers can only claim for SDA payments if an SDA-eligible participant resides in the dwelling.

> *"We recently observed 48 places remaining vacant, representing 21 per cent of our completed portfolio. This represents a significant risk to investors and their appetite in this asset class. We fear any slowing of filling vacancies will not only mean poor outcomes for NDIS participants, but could also have a chilling effect on private capital investing in SDA" – Anonymous[1385]*

This is exacerbated by inconsistencies in what SDA type and category participants are being funded for as compared with their level of need. QDN said:

> *"Many participants eligible for SDA aren't being funded at the level they require. For example, participants with more complex needs receiving Improved Liveability plans when they need to be Robust. There needs to be more funding for participants to*

match the level of support they require in and alongside their accommodation." –
Queenslanders with Disability Network[1386]

The changes in benchmark prices from the 2022-23 SDA Pricing Review recommendations will address some of the misalignment in supply and demand and more accurately price SDA vacancies, but many policy issues remain unresolved, as outlined in section 4.2.1.

4.2.3. SDA funding remains significantly underutilised

There also remains significant underutilisation of SDA funding. At 30 June 2023, around 2 in 5 participants with SDA funding in their plan did not, according to data from the NDIA, appear to be living in an SDA dwelling and/or claiming SDA payments (9,121 participants).[1387] This is on top of delays in assessment, confirmation of eligibility and funding allocations.[1388]

As an example, as at 30 September 2022, it took on average of 63 days to have SDA funding included in a participant's plan after the participant was assessed as being eligible for SDA, and a further 110 days for participants to be successful in locking that funding to their first SDA service booking.[1389]

> *"Many Specialist Disability Accommodation (SDA) homes are sitting vacant because of the wait times on approval of SDA for participants." – Queenslanders with Disability Network[1390]*

In addition to lengthy wait times, there are several possible explanations for why there is such underutilisation of SDA funding. For example, we heard that many participants eligible for SDA are not being funded at the level they require (see section 4.2.5), such as participants with more complex needs receiving Improved Liveability funding when they needed Robust.[1391] We heard that others cannot locate a suitable dwelling.[1392]

> *"SDA funding is granted but this in no way matches what is available in the area and this leads to regular inappropriate allocation. We wait forever for housing to be approved only to then be unable to utilise the funding." – Anonymous[1393]*

> *"Approximately 9,000 participants are experiencing barriers to moving into contemporary SDA, including inadequate funding and availability of suitable housing. To ensure participants can access SDA that meets their needs, there must be an adequate supply of the right kinds of SDA in the right locations." – Summer Foundation[1394]*

There may also be participants who have appropriate SDA funding, but are not yet ready to move, whether due to a personal preference to stay in their current arrangement while they explore options, or because they lack the support they need to explore their options. Additional support for these participants through Housing and Living Navigators (see Action 8.2), and the opportunity to trial new housing and living arrangements (see Action 8.3), should support greater utilisation of SDA funding.

4.2.4. Improved market data is required

A lack of market information contributes to provider/investor risk and continued hesitance in investing in SDA.[1395] There is general acknowledgment that the provision of SDA information and data has improved, but more is needed.[1396]

> *"the lack of information about supply and demand is a major barrier to having more people with significant disability living in suitable and affordable SDA housing as developers do not have the demand information they need to inform development decisions. This has improved over time but continues to be an issue." – National Disability Services[1397]*

> *"A significant barrier to good home and living outcomes for participants is incomplete market intelligence and information, particularly where it is difficult for the SDA sector to know in advance what housing is required where and for whom." – Anonymous[1398]*

> *"The NDIA needs to be more proactive as a market steward in relation to SDA housing supply and create data systems that track and facilitate investment decisions in relation to SDA stock that matches participant needs." – Queenslanders with Disability Network[1399]*

> *"As market steward, the NDIA must facilitate the provision of reliable and regular information that informs quality investment decisions aligned to the needs of participants." – Summer Foundation[1400]*

Part of the gap in information is the additional demand for SDA of those expected to be eligible for SDA, but not currently funded for SDA. According to one report: "the fact that so many people who were eligible for SDA funding were not yet receiving payments was not necessarily an indication of insufficient demand for housing, rather, administrative inefficiencies in identifying eligible NDIS participants and getting SDA funding approved. ... There are more than 1000 people with disabilities in hospitals right now who could be approved for funding and thousands in residential aged care. We know who they are, people just need the right money for housing and support. That's within the control of the NDIS to approach quickly and efficiently".[1401]

The SDA Alliance called for a commitment from the NDIA to commence a 'Demand Activation Program' in order to develop and publicly share data on the future housing needs of those participants already residing in SDA and of those in receipt of Supported Independent Living (SIL) funding only, and the release of detailed data of participants residing in residential aged care with a goal to move.[1402]

To address the gaps in market data and information and better align supply and demand, investors need:

- More detailed and frequent information on current and projected SDA demand by dwelling type and design category, by location, and on the features and characteristics of SDA supply and vacancies approvals.

- Comprehensive reporting of status against, and projections for, the timing of flows of residents in ageing SDA stock (Legacy and Basic) into New Build SDA (see section 4.32).

Effort should also be applied to the collection and regular sharing of data on changes in participant outcomes and support costs by SDA building types and design categories over time. This will inform what benefits can be realised from well-designed dwellings, and inform future needs for the continuation, promotion or cessation of particular SDA categories (see section 4.2.6).

4.2.5. Consistency in SDA decision making would benefit participants and investors

Submissions have raised concerns with an increasing number of SDA decisions that do not align with participant needs and which are often inconsistent with levels of support provided in SIL funding. For participants, this is causing frustration and fear of missing an available and suitable SDA solution, leaving them without suitable interim housing options, and limiting their ability to achieve their goals. It is also driving a large number of AAT processes, particularly where a participant's preference has not been supported by the NDIA.[1403]

For SDA providers, these delays and inconsistencies are sending the wrong market signals and posing a risk of withdrawal of provider investment due to lack of certainty in being able to obtain the expected return on investment.[1404]

> *"Certainty around the timing of SDA decisions would improve market certainty about how to plan projects and connect these to approved participants. This could also have the positive impact of reducing vacancies if providers are aware of decision timeframes and participants better understand the assessment process." – National Disability Services[1405]*

It was expected that the SDA market would be an open, competitive and dynamic market. In response, many SDA providers have invested time and resources to grow their presence in the marketplace. They have designed and invested considerable resources in processes that assist a person to explore options. NDIA decisions that are not what would be expected from the evidence result in stalled and withdrawn investment and significant loss to SDA providers that they are unable to recoup.

The proposed changes to improve the consistency and transparency of budget setting outlined in section 3 will, over time, be fundamental to delivering the certainty of decision-making required to retain SDA investment in the sector. Clear, comprehensive participant-facing materials to communicate the purpose and process to be approved for and move into SDA would also assist.

> *"When working efficiently and in a timely manner, NDIA decision-making benefits all stakeholders. For an investor, it provides a level of de-risking through reducing the period of vacancy and, for the participant, ensures that they can maintain their independence in suitable accommodation. Prompt decision making is also beneficial to the scheme itself – reducing the SDA benchmark price paid to the investor due to a reduced cost of capital." – Anonymous[1406]*

4.2.6. Ongoing innovation in SDA design categories is essential

Five SDA design categories have existed since 1 July 2016. The Basic design category can only apply to Existing dwellings (i.e. dwellings that had a certificate of occupancy dated prior to 1 April 2016) or Legacy dwellings (i.e. Existing dwellings that are designed to house six or more long-term residents). Additionally, Basic SDA funding cannot be included in a participant's plan except if the participant already lives in Basic design SDA, or if a participant chooses to reside in Basic design SDA.[1407] The five SDA design categories, an overview of their design features and the number of enrolled dwellings in each category as at 30 June 2023 is shown in Figure 98.

Figure 98: Overview of the five SDA design categories and the number of enrolled dwellings in each category at 30 June 2023[1408]

Basic — Housing without specialist design features but with a location or other features that cater for the needs of people with disability and assist with the delivery of support services. **There were 2,214 Basic dwellings enrolled at 30 June 2023 (27% of all enrolled SDA dwellings)**

Improved Liveability — Housing that has been designed to improve 'liveability' by incorporating a reasonable level of physical access and enhanced provision for people with sensory, intellectual or cognitive impairment. **There were 1,545 Improved Liveability dwellings enrolled at 30 June 2023 (19% of all enrolled SDA dwellings)**

Fully Accessible — Housing that has been designed to incorporate a high level of physical access provision for people with significant physical impairment. **There were 1,013 Fully Accessible dwellings enrolled at 30 June 2023 (12% of all enrolled SDA dwellings)**

Robust — Housing that has been designed to incorporate a high level of physical access provision and be very resilient, while reducing the likelihood of reactive maintenance and reducing the risk to the participant and the community. **There were 670 Robust dwellings enrolled at 30 June 2023 (8% of all enrolled SDA dwellings)**

High Physical Support — Housing that has been designed to incorporate a high level of physical access provision for people with significant physical impairment and requiring very high levels of support. **There were 2,664 High Physical Support dwellings enrolled at 30 June 2023 (33% of all enrolled SDA dwellings)**

SDA dwellings can also be enrolled in multiple design categories, but at 30 June 2023 there were only 22 Multi-Design Category SDA dwellings.[1409]

Requirements for each of the design categories is contained in a comprehensive *SDA Design Standard* that was released in October 2019 and supplanted the design guidelines contained in the SDA Price Guide from 1 July 2021.[1410]

The Improved Liveability SDA design category

The SDA Design Standard describes Improved Liveability SDA as "housing that has been designed to improve 'Liveability' by incorporating a reasonable level of physical access and enhanced provision for people with sensory, intellectual or cognitive impairment".[1411]

Sample features of Improved Liveability dwellings include:

- Continuous step-free access way from property boundary or onsite parking to entrance door of dwelling.
- Bedroom on entry level or level serviced by a lift and minimum bedroom size of 3100mm x 3100mm.
- Bathroom on entry level or level serviced by a lift; bathroom wall reinforcements for future proofing installation of grab-rails.
- Level and slip resistant surfaces, with minimum slip resistance standards.
- Enhanced lighting (e.g. dimmable, task lighting in kitchens) and consistent placement of switches - horizontally aligned with door handles and rocker switches.
- Luminance contrasts on doorways, toilet seats and colour contrast between floor and wall surfaces.

Box 46: Key facts on the Improved Liveability category of SDA as at 30 June 2023

- There were 1,545 SDA dwellings in the Improved Liveability design category, representing almost 1 in 5 (19 per cent) of all enrolled SDA dwellings.[1412] Around 40 per cent of these were New Build SDA, and just over half were Existing SDA, while 44 were Legacy SDA.[1413] There were also 283 Improved Liveability dwellings in the development pipeline, representing 8 per cent of all unfinished/unenrolled SDA.[1414]
- Excluding those who did not have a defined SDA category recorded, there were 5,162 participants with SDA funding in their plan seeking an SDA place (either to move from a current SDA place or because they were not yet in an SDA place), and around 40 per cent were seeking an Improved Liveability dwelling.[1415]
- 11,893 participants could be exactly matched to living in an SDA dwelling, with 1 in 5 (2,375) living in an Improved Liveability dwelling. These residents are much more likely to have a cognitive impairment, with the vast majority having a primary disability of intellectual disability, autism, Down syndrome, acquired brain injury or psychosocial disability (Figure 99).

Figure 99: Number of participants living in Improved Liveability SDA at 30 June 2023 by primary disability type[1416]
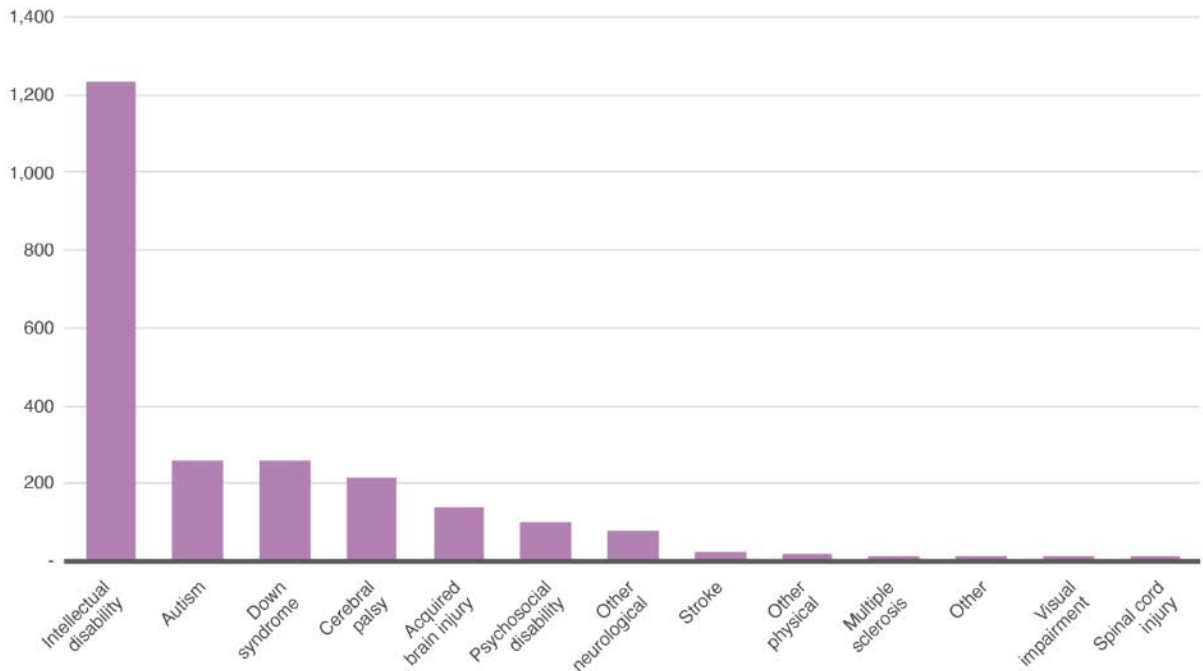
Following the 2022-23 SDA Pricing Review, New Build SDA prices increased significantly for Improved Liveability dwellings across all building types (Figure 100). The 2022-23 SDA Pricing Review stated that the rationale for these substantial increases to Improved Liveability dwellings was that there had been an underestimate in 'acquisition costs' (that is, land costs, build costs and other costs, such as stamp duty and conveyancing) for this category in the previous pricing model, which skewed construction activity away from these dwellings.[1417]

Figure 100: New Build SDA annual base prices for Improved Liveability before and following the 2022-23 SDA Pricing Review (no fire sprinklers, no onsite overnight assistance, GST not paid or credits claimed)[1418]

Building type	Pre-Price Review (2022-23 Base Prices)	Post Price Review (2023-24 Base Prices)	% Increase
Apartment, 1 bedroom, 1 resident	$38,664	$73,369	90%
Apartment, 2 bedrooms, 1 resident	$46,035	$77,260	68%
Apartment, 2 bedrooms, 2 residents	$17,985	$33,134	84%
Apartment, 3 bedrooms, 2 residents	$24,030	$41,238	72%
Villa/Duplex/Townhouse, 1 bedroom, 1 resident	$27,234	$53,073	95%
Villa/Duplex/Townhouse, 2 bedrooms, 2 residents	$17,044	$30,729	80%
Villa/Duplex/Townhouse, 3 bedrooms, 3 residents	$13,922	$25,123	80%
House, 2 bedrooms, 2 residents	$24,892	$61,092	145%
House, 3 bedrooms, 3 residents	$19,564	$42,852	119%
Group home, 4 bedrooms, 4 residents	$17,240	$35,425	105%
Group home, 5 bedrooms, 5 residents	$14,569	$29,542	103%

These increases closed the price gap considerably between the Improved Liveability and Fully Accessible design categories. Depending on the dwelling type, the difference is now as little as 2.2 per cent, and on average 3.7 per cent across all dwelling types.[1419]

In addition to incentivising the building of Improved Liveability dwellings, the recent increases may also support a reduction in vacancies because some SDA providers might now see it as financially viable to offer an SDA place in a higher cost design category to a participant funded for Improved Liveability. This is particularly likely if the alternative is no SDA revenue at all. However, this poses the question as to whether it would be simpler if, in light of the minimal price difference between the two, the Improved Liveability design category were removed and the market incentivised to build higher specification Fully Accessible dwellings that can support a wider range of participants with a wider range of disabilities.

Compared to Improved Liveability, the Fully Accessible design category offers:

- Larger bedroom(s) on an entry level or level serviced by a lift.
- Continuous step-free accessway from the property boundary to an entrance door of dwelling, with no concession that this be delivered via entry from a car space.

- Additional circulation space, e.g. wider accessway (1200mm), doorways (900mm), corridors (1200mm).
- Window controls that can be operated from either sitting or standing position.
- More accessible bathroom design, e.g. with larger showers and wider circulation around toilets.
- More accessible kitchen design, e.g. additional clearance in front of benches to provide comfort for people using wheelchairs, side-hinged ovens, drawer-dishwashers, height-adjustable benchtop surface, wheelchair-accessible pantry.[1420]

While Improved Liveability dwellings have some specific design requirements not required in Fully Accessible designs, these primarily relate to luminance contrast which could potentially be added after a dwelling is built through relatively low cost modifications.[1421]

On balance it is our view that the NDIA should remove the Improved Liveability category for new SDA builds, as it does not represent value for money. This will ensure that new SDA builds are focused on accommodation with specialist accessibility features (in the case of Fully Accessible and High Physical Support), specialist design features (in the case of Robust), or accommodation that is specifically designed to facilitate best practice sharing of supports (in the case of the proposed new SDA category – see section 4.4).

This does not, however, mean that participants will not be supported with their accommodation within the scheme.

In removing the Improved Liveability category for new SDA builds, there should be no change to the living arrangements for existing participants. Those currently living in Improved Liveability SDA should remain there.

There will be many participants transitioning out of ageing SDA stock (see section 4.3) who might have otherwise been eligible for the Improved Liveability SDA category. Many of those currently living in Basic stock are people with the same characteristics as those currently in Improved Liveability SDA — that is, with cognitive impairment, autism and psychological disability (Figure 101). However, many of these participants are older (see section 4.3.1) and some may be better suited to a Fully Accessible design.

These participants, as well as all new participants to the scheme, should be assessed according to their level of need (see Action 3.4) and be allocated funding for an alternative category of SDA. This could include the new shared support SDA category (see section 4.44). However, where transitioned participants have co-residents with higher support needs (requiring, for example, Fully Accessible or High Physical Support design categories) and they wish to continue to live with them, flexibility in SDA arrangements for this group should be supported as part of the strategy to deal with ageing stock (see Action 9.8).

Figure 101: Distribution of participants with an exact address match to living in an SDA dwelling, by primary disability type and SDA design category at 30 June 2023[1422]
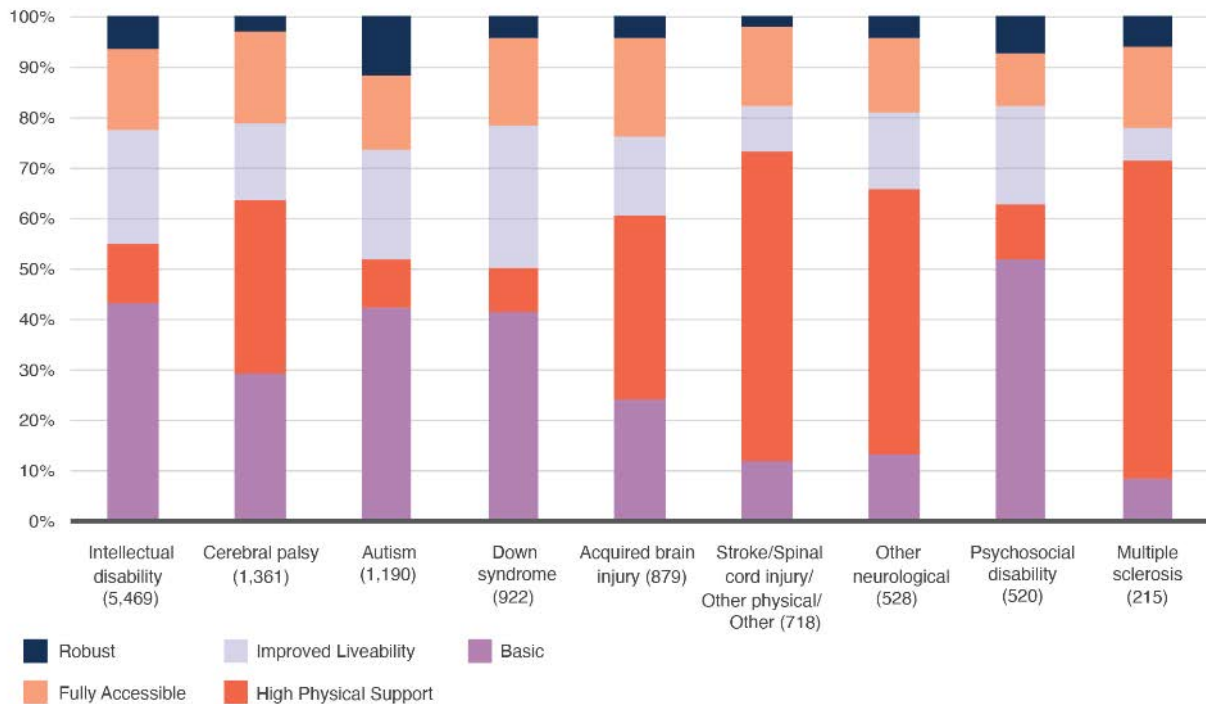
It will be important that, through the new whole-of-person budget setting approach, greater and more effective use of home modifications spending is made for those participants not found eligible for SDA. This will ensure that participants who need those features of improved liveability housing that can be more easily retro-fitted into existing properties, such as luminance and colour contrasts and dimmable lighting, can be funded for this in their home modifications budget.

It is also worth noting that the introduction of the Livable Housing Design Standard in the National Construction Code (NCC) (see section 4.4) will represent a move towards general housing stock that has some similarity to Improved Liveability Dwellings.

That said, we heard that there are many differences between the two, including that the SDA Improved Liveability Design Standard is specifically focused for people with disability, whereas the NCC Livable Housing Design Standard is targeted at the general population.[1423] For example, corridor width requirements are greater in the Improved Liveability SDA Design Standard than the NCC Livable Housing Design Standard,[1424] and the SDA Improved Liveability Design Standard includes additional requirements such as luminance contrast features to support people with low vision to distinguish between surfaces.[1425]

There are also many ways in which developers can get around the NCC Livable Housing Design Standard, such as exemptions based on site suitability, whereas the SDA Improved Liveability Design Standard is more concrete and does not permit exemptions.[1426] The Improved Liveability SDA Design Standard is therefore considered to be better than the NCC Livable Housing Design Standard in meeting the needs of as many people as possible.[1427]

Nevertheless, the application of the NCC Standard would introduce basic accessibility features into the general housing stock. This is discussed further in section 4.4.

Reviewing the SDA categories and design standards

Some stakeholders have questioned whether the SDA design categories reflect contemporary, and future, needs.[1428]

> *"The categories (eg Robust, Fully Accessible, Improved Livability) are too rigid. There needs to be flexibility, as individuals can require certain features from different categories without requiring the whole category ... The funding should be targeted at the needs the individual has, not a rigid category which may not provide all features required." – Consultation, Every Australian Counts[1429]*

In 2019, the NDIA released the SDA Innovation Plan. This was designed to increase awareness of the transformation needed in disability housing and living supports, promote the benefits of SDA innovation on participant outcomes, remove barriers to the adoption of inclusive and innovative models, and keep pace with emerging ideas.[1430] Progress against the objectives of the plan do not appear to be readily available.

However, there are exciting examples of good practice and innovation using SDA design principles and features to achieve better outcomes for participants. In particular, the work by the Victorian Government in designing person-centred Robust SDA demonstrates a natural and important link between the built environment (building location, features and design) and participant outcomes.[1431]

> *"The impact of the design is massive ... it can have a really positive effect on people and their behaviours, but if it's inadequately designed it can have the reverse effect where people's behaviours remain or get worse." – Stakeholder, Homes Victoria Designing person-centred robust Specialist Disability Accommodation[1432]*

While the SDA design categories have made significant improvement to the built fabric for people with specialist accommodation requirements, best practice would indicate that the design standards and funding required to best meet participant needs should be reviewed on a regular basis. The NDIA's 2019 *SDA Design Standard Implementation Plan* specifically noted the *SDA Design Standard* would be reviewed by the NDIA in 2023, but this has not proceeded as planned.

A review of the SDA categories and associated design standards is timely. The NDIA should immediately start working with the sector and participants to establish a review. The review should be conducted by a team with a wide range of expertise, to reflect its broad nature covering both the SDA categories and design standards, and build on the experience of participants, their families, support workers, providers and investors.

The review should evaluate how fit-for-purpose the remaining three SDA categories are, and how well they enable delivery of best practice and cost-effective shared living supports. In doing so, it should examine ways in which contemporary support practices can be incorporated into the built

environment, and how greater independence and connection to communities, consistent with the wider population, can be achieved. Increased individualisation of living arrangements while sharing support costs effectively, and so considering SDA and SIL together, should be another key focus of this review. This has not been a feature of previous reviews of SDA design categories.

The review should also look at whether the Robust category's design features adequately capture the range of needs of the participants it caters for. For example, one report identified that Robust SDA caters to people with a diverse range of disabilities, sensory needs and behaviours and noted that the diversity of resident needs made it more difficult to pinpoint and apply standard design guidelines to build Robust SDA in comparison with other SDA design categories.[1433]

Other issues that the review should take into consideration include:

- the appropriateness of location density requirements, including to what extent multiple SDA in the one street is appropriate
- the need for greater flexibility in the design standards in limited circumstances
- appropriate support for individual and shared support needs
- optimal safety for residents and support workers
- ways to reduce and eliminate restrictive practices (see Recommendation 18)
- funding and design options to allow SDA-funded participants and people who are not NDIS participants, such as participants' family members, to live together without the scheme subsidising the entire accommodation
- adapting design to environmental considerations and ensuring energy and water efficiencies
- multi-category designs
- more culturally appropriate designs
- how to make the house feel like a home including location of onsite overnight assistance or office space for the support provider
- the optimal number of bedrooms and bathrooms
- accessibility requirements to support older participants to age in place
- examples of innovation and emerging best practices, since the NDIS commenced.

The 2022-23 SDA Pricing Review recommended that the NDIA examine, in consultation with participants and providers, the costs and benefits to participants and to Scheme sustainability of amending the SDA Pricing Arrangements to phase out the ability of new four or five-bedroom Group Homes to be enrolled as SDA dwellings.

While we do not make a specific recommendation on this point, we note our recommendation that funding for 24/7 living supports should, in general, be on the basis of 1:3 is a clear signal to the market that new four and five bedroom SDA dwellings will not be needed. There may be circumstances where more than three people wish to share and so larger (four and five bedroom) houses should continue to be permitted, but any ongoing vacancy risks beyond three people should be borne by the SDA owner.

The review of the SDA categories should also design the standards and features that will apply to the new shared living category of SDA (see Action 9.10).

Finally, the review should also consider how the SDA Design Standards could better align with the building classification system of the NCC. This is important given that there is currently a lack of clarity about the building classification — Class 1b or Class 3 — that applies to SDA dwellings (see Box 47).[1434] Inconsistency in the application of building classifications can, due to the difference in cost of building to the different classification, lead to 'gaming' the classification system, where developers improperly classify to maximise financial return because one classification is cheaper than the other.[1435]

> *"SDA Alliance members and other stakeholders have described to the SDA Alliance instances where they understand Building Certifiers are being misinformed about the intended use of an SDA dwelling, to avoid the requirements of Class 3 builds so as to achieve Class 1 certification. In these instances, the Class of building being specified is sometimes much lower, without the safety features that are necessary to protect the safety of residents, particularly in the event of fire. In other instances, the SDA Alliance and its members are aware of instances where the requirements of Class 3 are more than is reasonably required by the intended tenants and the cost of construction so high that the projects are abandoned as they are financially unviable, resulting in participants not being housed." – SDA Alliance[1436]*

To remedy the confusion, SDA Alliance has called for a new classification, Class 1C, to be established in the NCC specifically for SDA.[1437]

Box 47: Building classification of SDA

Within the NCC, Building Classes have been developed to ensure that building designs meet minimum standards relative to their intended use. The 4 Classes of buildings that relate to private accommodation are:

- Class 1a - a single dwelling being a detached house; or one of a group of attached dwellings being a town house, row house or the like.
- Class 1b - one or more buildings which together constitutes a boarding house, guest house, hostel or the like that would ordinarily accommodate not more than 12 people and have a total area of all floors not more than 300 m2.
- Class 2 - a building containing two or more sole-occupancy units such as an apartment building. Each sole-occupancy unit in a Class 2 building is a separate dwelling.
- Class 3 - residential buildings other than a Class 1 or Class 2 building. They are a common place of long term or transient living for a number of unrelated people. Examples include a boarding house, guest house, hostel or backpackers (that are larger than the limits for a Class 1b building). Class 3 buildings may also be 'care-type' facilities such as accommodation buildings for children, the elderly, or people with disability, which are not Class 9 buildings.[1438]

The SDA Rules set out the Building Code of Australia classification for each building type.[1439] But in most cases, it is not clear cut. For example, for a group home (identified as having 4 or 5 long-term residents) this would be classified as Class 1b or 3.[1440] The SDA Design Standard does not provide any further clarity and leaves the exact regulatory classification of SDA to the NCC.[1441] However, the NCC does not specifically reference SDA within any defined building class. It does refer to accommodation for "people with disability" among the examples provided in the definition of a Class 3 building, though it is unclear whether this reference to disability means all accommodation for SDA must be Class 3.[1442]

The issue was considered in the recent SDA Pricing Review, which noted mixed views amongst stakeholders about the classification of SDA as NCC Class 3 buildings or as Class 1b buildings.[1443] On the one hand, some expressed concerns about the additional construction and compliance costs incurred with building to the provisions of Class 3, and that these buildings may reduce the participant's sense of homeliness. However, other stakeholders reported that building to the Class 3 standard provides additional protections from fire, injury, or other hazards for participants.[1444] The SDA Pricing Review recommended that the NDIA and the DSS work with the Australian Building Codes Board and other relevant government and industry stakeholders to:

- Provide greater clarity to the sector as to whether the NCC prevents SDA dwellings from being classified as Class 1 Buildings.
- Develop a long-term approach to the classification of SDA dwellings in the NCC that protects the human rights of people with disability to housing choice, appropriately protects SDA resident participants against fire risks, and provides for a more ordinary home-like environment than that required under Class 3 in the NCC.[1445]

A review of SDA categories and design standards is an appropriate vehicle for bringing all affected parties together to clearly align the SDA Rules and Design Standards with the building classification system of the NCC.

4.2.7.   SDA price setting arrangements should be independent and more flexible

SDA prices are currently set in accordance with the SDA Pricing and Payments Framework. The Framework is designed to promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and achieve full inclusion in the community.[1446]

In 2023, the first five-yearly review of SDA pricing was conducted. The specifics around SDA price levels is outside the scope of this Review, but the way prices are set and by whom was considered.

Independent SDA price setting

We think there is a need to strengthen transparency, independence and credibility in the pricing of SDA and remove the conflict that the NDIA has in setting market prices as well as achieving

sustainability objectives. To achieve this, responsibility for advising on SDA prices should move to an independent pricing authority.

Independent price setting for SDA has been called for by others in the past.[1447]

> "… we strongly believe that price setting and market custody of the SDA (and potentially the broader provider) market as well as its budgetary accountability should be the responsibility of an independent function with specialists who have substantial experience in infrastructure or regulated markets, and a long-term perspective of the key features of an efficient operating market. This would go some way to ensure the consistency of the sector and catalyse ongoing private capital." – Anonymous[1448]

To align with the recommended pricing arrangements for other NDIS supports (see Action 11.3), we think the appropriate body to take on the role of SDA price setting is the Independent Health and Aged Care Pricing Authority (IHACPA). The Australian Government, in consultation with state and territory governments, should make the final determination on SDA prices based on IHACPA's advice.

SDA is a unique, never experienced asset class that operates within a complex demand and budget framework. Pricing signals are the most responsive, time and value sensitive lever available to government to steer the market in the required direction. The expertise to get this pricing level right, within the right timeframes, without inappropriately over stimulating or dampening the right type of long term professional investment is critical to the success of the model.

IHACPA will therefore need to ensure that they build appropriate skills and expertise including detailed knowledge of the SDA design standards, building and land costs, property ownership costs, investment structures, taxation strategies, capital asset pricing models and best-practice approaches to pricing of regulated assets.

More flexible SDA pricing

A key priority for the approach to SDA pricing needs to be to encourage innovation and inclusion. Crucial to this is having flexibility in the pricing approach. Base SDA prices are currently adjusted by location factors based on Australian Bureau of Statistics (ABS) Statistical Area 4 (SA4) regions.[1449] These are wide geographical areas that do not account for variations in land cost within each region, which can be substantial.

Flexibility in the pricing framework should be introduced through a process that would allow IHACPA to price certain dwellings above the relevant price cap, by exception.

One relevant exception could include dwellings in higher cost locations within an SA4 region that would not be viable when applying the SA4 location factor. This would allow participants living in higher-cost suburbs to maintain connection to their community when they move into SDA. This will be particularly important as participants living in ageing SDA are, over time, transitioned into more contemporary SDA in line with their wishes. This could also allow participants to be closer to their informal support networks which build natural safeguards and can decrease the quantity, and therefore costs, of formal paid support.

Another exception could be to allow for multi-category needs, such as for participants who require the features of both Robust and High Physical Support categories. The current approach is likely not working — at 30 June 2023 there were only 22 multi-design category SDA dwellings, representing only 0.6 per cent of all enrolled New Build SDA dwellings.[1450]

The 2023 SDA Alliance and Urbis *SDA Pricing Review Summary Report* indicated that the median cost for building a multi-design category dwelling is up to 77 per cent more than a single design category despite the fact that they support participant choice in co-tenants, increase the pool of potential residents for a dwelling, and may reduce vacancies.[1451] In rural areas, active investment in multi-design category SDA dwellings also lends itself to innovative models of use for NDIS participants as well as aged care and respite services to provide a more holistic solution to community needs.

The process for permitting SDA prices above the cap should be developed as a collaboration between IHACPA, the NDIA and the sector. It should include an approvals process for determining which dwellings would be referred to IHACPA for pricing on an exceptions basis.

The SDA pricing framework will also need to be adjusted in due course, in line with the results of the review of the SDA categories and associated design standards (see section 4.2.6).

4.2.8. Targeted commissioning is needed in some cases where the private investor model cannot deliver

The changes outlined throughout this section are designed to ensure that the private investor model of SDA delivery can function effectively and bring about an alignment of supply and demand of the right dwellings in the right locations. But there are some instances where the private investor model simply cannot deliver.

Our proposal to introduce more flexibility into the SDA pricing framework will help to some extent. It will ensure that SDA providers are encouraged to explore the development of innovative and inclusive solutions where otherwise rigid pricing frameworks may have excluded them from being considered. But in some cases, this will not be enough.

As explained in chapter 4, direct commissioning can be appropriate in thin markets where competition is not possible. This is likely to be required to address the challenges for rural and remote areas, where demand is smaller and characterised by mixed levels of need. This increases the level of risk faced by investors, who may refuse to invest in these areas. In 2021, the Summer Foundation prepared a report on SDA in thin markets, summarising the challenges supplying SDA in rural and remote locations as:

- Workforce shortages, including a lack of allied health professionals to prepare functional assessment reports for participants when applying for SDA, as well as a scarcity of building and construction workers.
- Unknown demand driven by poor demand data from the NDIA and limited knowledge of the local market from SDA providers, particularly if they are not from the community.

- Financial risk. While there is an element of financial risk in all SDA developments, these are compounded in rural and remote regions where development costs can be higher and returns less certain due to a smaller pool of participants funded for SDA.
- Challenges with market coordination, including additional resourcing required to effectively engage with local communities and service providers. [1452]

Taken together, these challenges may be insurmountable in some locations, leaving direct commissioning of SDA as the only viable approach.

For remote First Nations communities, commissioning can be particularly important to ensure that SDA is sensitive to the cultural needs of First Nations participants, and allows them to maintain connections to country.[1453] Connections with community leaders and local councils are also important.[1454] There are also complexities with securing land from land councils, which need to be managed.

> *"...there is no cultural requirement related to SIL or SDA housing stock and this should be revised to ensure that First Nations participants are given a house that is culturally safe. This could be as simple as ensuring that there is a fire pit a place for a smoking ceremony, a place for yarning circles, pictures that are First Nations specific." – Participant[1455]*

Commissioning is also likely to be required for participants with specialised needs that require individualisation of design solutions, for example, so called 'Robust+' accommodation.

> *"...some participants have disability-related needs that require SDA which includes features from more than one SDA design category, such as High Physical Support and Robust, and other participants have needs for incredibly high-cost and bespoke Robust SDA or incur excessive reactive maintenance costs while transitioning to a new environment or while trialing innovative new approaches that seek to remove needs for restrictive practice. Similarly, participants from remote, First Nations communities may require a bespoke SDA solution that is not currently provided for in the SDA Design Standard and corresponding SDA pricing arrangements." – SDA Alliance[1456]*

A similar approach was recommended in the 2022-23 SDA Pricing Review, with the final report recommending that the NDIA establish "regular rounds of funding for demonstration/pilot/bespoke projects" for participants whose housing "needs are unable to be adequately met by the current SDA Design Standard and pricing arrangements".[1457]

It has also been recommended by the SDA Alliance that a formal mechanism be established to allow for participant outliers whose needs are unable to be adequately met by the current SDA Design Standard and pricing matrix. They recommend a Home & Living Innovation Hub with regular rounds of funding for projects to serve participants with specific needs, spark ongoing evolution of the scheme, and enable projects that enhance scheme sustainability.[1458]

We believe that active and multi-faceted market stewardship is required to commission SDA. While commissioned SDA would be funded by the scheme, effective stewardship would see

commissioning in remote areas undertaken in partnership with state, territory and local governments to enable utilisation of their existing expertise, workforces, networks, and infrastructure. This would also optimise the potential for cross-sector approaches, opening the possibility of innovative solutions that can meet broader community needs. Similarly, commissioning SDA for participants with highly complex and specialised needs would be funded by the NDIS but undertaken, regardless of location, in collaboration with state and territory government authorities with expertise relevant areas such as forensic disability services and mental health.

4.2.9. Active market oversight and separation of SDA and support providers is needed

Participants and their families need greater assurance of the quality of SDA offerings and associated support arrangements. This is essential for enabling them to exercise informed choice and achieve the quality of life benefits that SDA is designed to deliver.

While all SDA providers must be registered, we have heard that there is limited awareness and understanding of the SDA Practice Standards and associated quality indicators amongst some SDA providers.[1459] We heard of issues with the tenancy management component in the SDA Practice Standards, which requires documented arrangements to be in place with each participant and their other NDIS providers that deliver SIL supports within a SDA dwelling, to outline roles and responsibilities on a range of matters. There are reports that these requirements are poorly understood and complied with by SDA providers.[1460]

We were told about participants not being aware that their SDA provider had contracted a specific SIL provider in a combined service agreement, and participants were not given any opportunity to discuss how they wanted to manage their service agreements with the separate SDA and SIL providers.[1461] We also heard of SDA providers failing to give participants full access to information or alternative support options, or to advise participants of their rights to identify and raise safety concerns.[1462]

We have also heard of problems relating to the enrolment of SDA dwellings. While the NDIA is responsible for the enrolment of dwellings under the SDA Rules, SDA providers also have obligations under the Practice Standards maintained by the NDIS Commission.[1463] The Practice Standards require that enrolled SDA dwellings meet the design type, category and density restriction requirements set out in the SDA Rules.[1464] We have heard concern about poor quality and non-compliant enrolled SDA dwellings. This includes instances where enrolled SDA dwellings do not meet the specified design category or building type requirements, breach density restrictions, or have never been inspected by a third party and may therefore not meet dwelling enrolment requirements.[1465]

The NDIS Commission acknowledged a lack of compliance with the SDA Practice Standards in its Own Motion Inquiry into Aspects of Supported Accommodation. It stated that it will consider a future compliance campaign targeting SDA providers and their obligations under the Practice Standards, particularly in regard to tenancy management.[1466]

Greater visibility and active intervention by the new National Disability Supports Quality and Safeguards Commission and the NDIA in the monitoring and enforcement of compliance with the SDA Practice Standards and the associated quality indicators is needed to ensure that SDA dwellings are managed in accordance with the needs of participants. In particular, they need to:

- Monitor how SDA providers are working with other providers to ensure the arrangement is working effectively for participants, in line with tenancy management requirements in the Practice Standards.[1467]
- Ensure that enrolment of SDA dwellings meet the requirements of the design type, category and density restriction of the SDA Rules.[1468]

The SDA Rules are clear on the importance of social and economic participation in considering the building type and location of SDA.[1469] While there is no requirement for compliance against this in the Practice Standards, the NDIA should, over time, track how well the sector is faring on this front. To date there is limited evidence that SDA has been effective against these expectations, though such an assessment is hindered by poor data. Analysis on the location and type of SDA that is built, and how it impacts on participant outcomes and future support costs, will enable better consideration of how well social and economic participation is being facilitated by SDA (see also section 4.2.4). Ensuring that Community Visitor Schemes are aware of new stock and able to visit them will also help to support the wellbeing of participants residing in SDA (see Action 16.4).

Mandating the separation of SDA and living support providers

We have received significant feedback about issues with conflict of interest in the provision of housing/accommodation supports, and living supports.[1470] This applies both specifically for SDA, but also for non-SDA accommodation such as SIL homes.

We heard that where a single provider delivers both SDA and living supports this can result in participants not being provided with genuine choices, lead to poor participant outcomes and unnecessary scheme costs.[1471]

These concerns have been echoed in other reports and inquiries.[1472] The Joint Standing Committee on the NDIS observed an emerging trend of SDA providers "pre-selecting" SIL providers to operate exclusively in a dwelling.[1473] The Committee acknowledged that mandating SIL and SDA be delivered by separate entities may affect the availability of supply, but considered nevertheless that "service delivery should be separated from tenancy management so far as possible".[1474]

The Summer Foundation's *Separation of Housing and Support Position Paper*, published in 2021, highlighted many issues that can arise when a single provider delivers both housing and support services. These included:

- Weakening a participant's appreciation of their right to choose their preferred living support provider and reducing their awareness of different support options.
- Limiting a participant's understanding of the separate responsibilities of their SDA provider and their living support provider.

- Reducing a participant's ability to distinguish the separate delivery of their housing and living support services.
- Creating pressure on a participant to use 'in-house' support services and impacting on participant confidence to make a complaint or raise a concern.
- Creating a 'closed system' that reduces service provider transparency and accountability and increases the risk of abuse, neglect, violence and exploitation of people with disability.[1475]

> *"The benefits are two areas of life are separate so the person who is providing your home is not providing your daily activities and personal care. Therefore if something is wrong with one of them you have the option to just change just one of them. The impact is that it takes away the fear of upsetting someone, if it's all together in one organisation then all other areas of your life can suffer. When housing and supports are separate you have more power over your choice and control, it takes away the fear. In my son's current situation even now, he's not committed to anybody, he has choice to move and it doesn't affect anyone, he will still have his own choice of support, this would not have to change with a move. Compared to when he lived in a group home where there was no choice." – Linda, mother of SDA participant from Summer Foundation Separation of Housing and Support Policy Position Statement[1476]*

The NDIS Commission, in its Own Motion Inquiry into Aspects of Supported Accommodation, had a different perspective, noting that it was not evident that providing both SIL and SDA to a person exacerbates issues in the quality and safety of supports for NDIS participants.

> *"The interaction between SDA and SIL provision requires further detailed exploration. It has been suggested by some stakeholders that steps should be taken to mandate a separation between the provision of SIL and SDA. The Inquiry has observed that in some situations this separation can in fact exacerbate issues of participant safety, if the SDA provider is not closely connected to the NDIS participants and their other support providers, and attuned to issues that are arising in a house." – NDIS Commission[1477]*

However, as noted in section 2.3.1, based on submissions and evidence presented, we believe that the interests of participants are better served through implementation of a more risk-proportionate model of regulation for the whole provider market (see Action 17.1) and further work to proactively respond to emerging and longstanding quality and safeguards issues by the new National Disability Supports Quality and Safeguards Commission (see Action 17.6), including issues such as conflicts of interest.

The separation of SDA and living support providers is currently not mandated. Instead, through the Practice Standards, the NDIS Commission regulates how organisations manage, rather than remove, conflicts of interest. SDA providers are required to proactively manage and document perceived or actual conflicts of interest.[1478]

The 'Conflict of Interest' requirements in the SDA Practice Standard requires that each participant's right to exercise choice and control over other NDIS support provision is not limited by the participant's choice of SDA dwelling.[1479] This includes a requirement that where a SDA provider is delivering both SDA and other NDIS supports to the same participant, there are separate service agreements.[1480] Participants must be supported to understand the distinction between the provision of SDA and other NDIS supports delivered in the dwelling.[1481] Organisational policies are also required to be in place, detailing how perceived or actual conflicts of interests are managed and made available to participants in the language, mode of communication and terms which each participant is most likely to understand.[1482] The Practice Standards also stipulate that a participant's housing rights, including security of tenure, are upheld, irrespective of any decision(s) they make about the provision of other NDIS supports within the SDA dwelling.[1483]

Many in the sector believe that these requirements are not sufficient to protect participants. The Independent Advisory Council to the NDIS expressed concerned that the practice of managing, rather than avoiding, conflict of interest has not been effective for participants who live in shared supported accommodation.[1484] Where a provider has competing interests, the stability, quality and safety of a participant's home and their right to exercise genuine choice and control is limited or removed.[1485] Real or potential conflicts of interest can also prevent participants raising concerns or complaints about supports due to fear of impacting on the delivery of other services.[1486]

Many have long called for separation to remove the conflict of interest and ensure participants are able to exercise genuine choice and control over their housing and living supports.[1487] A recent South Australia Parliamentary Inquiry completed in 2023 recommended improved rules regarding conflict of interest concerning the provision of SDA, SIL and support coordination to ensure that participants cannot be captured by service providers.[1488] The Joint Standing Committee on the NDIS also heard that the Practice Standards should do more to address conflicts of interest in SIL and other settings.[1489]

The Disability Royal Commission also noted that the NDIS Commission's Action Plan following its Own Motion Inquiry into Aspects of Support Supported Accommodation "does not sufficiently address the conflict of interest that can result from providers supplying both accommodation and support services".[1490] It recommended that the NDIS Commission prioritise the implementation of its Action Plan and that it be expanded to include "a specific review of mechanisms to transition away from allowing the same provider to provide Supported Independent Living and Specialist Disability Accommodation services, with interim arrangements to strengthen oversight to address and monitor conflicts of interest".[1491]

We agree with this view and recommend legal and practical separation of SDA (ownership and property management) and living support providers. The separation of housing and support would enable a participant to change their living support provider without fear of adverse consequences, ensures greater accountability and transparency of service delivery, and encourages specialisation and expertise in housing management or support provision.[1492]

While participants funded for shared 24/7 living supports would need to use the same living support provider to deliver their shared supports (section 4.1.6), having a separate housing

provider would enable the group (with the help of their independent Shared Support Facilitator) to choose another support provider if that was their collective preference, without forcing them to move. This separation should be through new or amended Practice Standards as part of implementing the Review's recommended graduated and risk-proportionate regulatory model (see Recommendation 17).

Ensuring independence between housing and other NDIS supports requires more than separate service agreements.[1493] Without both legal and practical separation, the issue of conflict of interest will continue to bring risk to participant safety, compromise housing security and limit or remove a participant's right to exercise genuine choice and control.[1494] The Summer Foundation published a toolkit in 2017 to help housing and living support providers understand how to separate their services.[1495]

There may be limited cases where separation is not possible. This might apply in rural and remote areas where there is a shortage of providers.[1496] There may also be cases where separation would be inappropriate for cultural safety reasons or situations where separation would prevent dwellings being well positioned to where participants wish to live.[1497]

A further exception we heard could be where it can be demonstrated that a participant is making an informed choice, demonstrating full knowledge of available options, and sufficient mechanisms have been put in place to ensure quality and safeguarding is not compromised as a result.[1498]

Any exceptions to the requirement for separation should be clearly documented and appropriately monitored.

Box 48: A word on structural separation outside of SDA accommodation

As outlined in section 2, closed systems also exist outside of SDA, in settings such as SIL homes and SRSs. The same issues that arise from the closed systems outlined in this section also apply to these non-SDA settings. Under our package of recommendations, all participants eligible for 24/7 livings supports would be eligible for an SDA payment (see section 4.4). This means that no participant receiving 24/7 living supports would be forced into a closed system arrangement with a non-SDA provider. All participants receiving 24/7 living supports would be able to live in an SDA enrolled property that is subject to the mandatory requirement of separation.

Those who do not require 24/7 living supports would be able to choose a housing arrangement that is managed by their living support provider. We are not recommending a requirement for separation outside of SDA as it is beyond the scope of this Review. However, several of our other proposals will provide added protections for participants not eligible for 24/7 living supports, including graduated, risk-proportionate regulation of all providers (see Recommendation 17) and the support of Navigators (see Recommendation 4) and independent Shared Support Facilitators (see Action 8.4).

4.2.10. Action & Implementation Details

Action 9.3: The <u>National Disability Insurance Agency</u> should release more detailed and frequent information on participant demand for 24/7 living supports and Specialist Disability Accommodation (both medium and longer term needs)

Data and information should be published quarterly and include current and projected Specialist Disability Accommodation (SDA) demand, current vacancies, and the features and characteristics of SDA dwellings both completed and in the pipeline. This should be complemented by information on participant preferences and best practice shared living arrangements gathered by Housing and Living Navigators (see Action 8.2) from interactions with participants. Frequent publication of detailed data should ensure the SDA market can respond by building the right types of dwellings in the right locations.

Implementation detail:

- The NDIA should publish more detailed and frequent information (at least quarterly) on SDA demand and supply on the centralised online platform (see Action 10.1). This should include data on:

  - Current and projected SDA demand, including details of SDA decisions by building type, design category and location. This should include projections of the anticipated timing of flows from Legacy and Basic stock into new build SDA.

  - Features and characteristics of SDA dwellings in the pipeline and completed.

  - SDA vacancies, by building type, design category and location.

Action 9.4: The <u>National Disability Insurance Agency</u> should remove the Improved Liveability category for new Specialist Disability Accommodation (SDA) developments, and review the remaining SDA categories and associated Design Standards to evaluate their effectiveness.

The Improved Liveability category should be replaced by alternate Specialist Disability Accommodation (SDA) design categories which meet the assessed needs of participants. The review should be conducted in consultation with participants, the SDA sector and disability community. It should examine whether the High Physical Support, Fully Accessible and Robust categories are fit-for-purpose and enable delivery of best practice and cost-effective living supports for the diversity of SDA participants. It should also consider how the building classification system of the National Construction Code and the SDA Design Standards could be better aligned.

Implementation detail

- The NDIA should immediately start work with the sector and participants to establish a review of the SDA categories and associated Design Standards. The review should:

  - Be conducted by a team with a wide range of expertise, to reflect its broad nature covering both the SDA categories and design standards.

  - Evaluate how fit-for-purpose the High Physical Support, Fully Accessible and Robust categories of SDA are, and how well they enable delivery of best practice and cost-effective shared living supports. This should include examining the appropriateness of location density requirements and the need for greater flexibility in the design standards in limited circumstances.

  - Set the design features and standards for the new shared living SDA category (see Action 9.10).

  - Work with the Australian Building Codes Board to ensure that the SDA Design Standards align with the building classification system of the National Construction Code.

- The revised SDA categories and associated design standards should be implemented through changes to the SDA Rules, including the removal of Improved Liveability and the introduction of the new shared living SDA category.

- In implementing these changes, there should be no change to the living arrangements for existing Improved Liveability participants.

- New participants and those transitioning out of ageing SDA stock who might have otherwise been eligible for Improved Liveability category, including those with intellectual disability, should be assessed according to their level of need (see Action 3.4) and be allocated funding for either a Fully Accessible SDA dwelling or the new shared support SDA category.

- Where transitioned participants have co-residents with higher support needs (requiring, for example, Fully Accessible or High Physical Support design categories) and they wish to continue to live with them, flexibility in SDA arrangements for this group should be supported as part of the strategy to deal with ageing SDA stock (see Action 9.8). They should also be given priority access to vacant existing Improved Liveability SDA stock.

Action 9.5: The Australian Government should transition responsibility for advising on Specialist Disability Accommodation pricing to the Independent Health and Aged Care Pricing Authority and introduce more flexibility to the way prices are set.

The remit of the Independent Health and Aged Care Pricing Authority (IHACPA) should be expanded to advise on pricing and costing matters for Specialist Disability Accommodation (SDA) to strengthen transparency and independence in the pricing of SDA, and align with the

recommended pricing arrangements for other NDIS supports (see Action 11.3). IHACPA should promote investment in the right types of dwellings in the right location. The SDA pricing framework should also be revised to allow flexibility for IHACPA to price certain dwellings above the price cap by exception. Relevant exceptions could include dwellings in higher cost locations to maintain a participant's connection to their community, or to allow for multi-category needs.

Implementation detail:

- Development of this update to the SDA pricing framework should include:

  - IHACPA working with the sector and the NDIA to develop a mechanism for price certain dwellings above the price cap by exception.

  - The NDIA developing, together with the sector, an approvals process for determining which dwellings would be referred to the Pricing Authority for pricing on an exceptions basis.

- IHACPA should be resourced adequately, with the right expertise, to perform this function.
- IHACPA should obtain advice on approaches to pricing regulated assets to give the market more confidence.

Action 9.6: The <u>National Disability Insurance Agency</u>, in consultation with state and territory governments, should commission Specialist Disability Accommodation where needs are not adequately met by the private investor model.

Specialist Disability Accommodation should be commissioned for participants living in remote locations, and for participants with very specialist or complex needs (such as those requiring forensic housing). The National Disability Insurance Agency should work in partnership with communities (see Recommendation 14) and state and territory governments, who deliver both public housing and specialist disability housing, to design, deliver and evaluate a pilot approach to assess how a commissioned model can deliver better supply and outcomes for participants before implementing at scale.

Implementation detail:

- The NDIA should work with the sector to pilot a commissioning model, including:

  - determining in which circumstances alternative commissioning is required

  - what models should be trialled

- how to ensure the commissioning model is within the scope of the regulatory arrangements of the new National Disability Supports Quality and Safeguards Commission (see Action 17.1).

- Once complete, it should evaluate the pilot approach and begin implementing the program of alternative commissioning at scale.

Action 9.7: The new <u>National Disability Supports Quality and Safeguards Commission</u> should strengthen Specialist Disability Accommodation (SDA) regulation to ensure dwellings are managed in accordance with the needs of participants and mandate the separation of SDA and living support providers.

Monitoring and enforcement of compliance with Specialist Disability Accommodation (SDA) practice standards should be strengthened. The legal and practical separation of SDA and living support providers should also be mandated, with limited exceptions, and monitoring and enforcement of compliance arrangements put in place (see Action 17.1). Any exceptions to the requirement should be clearly specified, for example, in remote areas where separation is not feasible.

Implementation detail

- As part of its work to implement a graduated risk-proportionate regulatory model (see Action 17.1), the new National Disability Supports and Quality and Safeguards Commission should consult with people with disability, providers and other regulators in revising the SDA Practice Standard to mandate separation of SDA and living support providers. This work should:

  - Have regard to the interaction with new or amended support-specific Practice Standards for different housing and living supports, including a new Practice Standard for providers delivering 24/7 living supports.

  - Determine the circumstances under which separation of SDA and living support providers can be bypassed.

- Monitoring and enforcement of compliance with the SDA Practice Standards should be strengthened in line with the risk-based and more active approach to compliance activity outlined in Action 19.3.

4.3.   Ageing SDA stock remains unaddressed

We define ageing SDA as Legacy dwellings in any design category and all dwellings with a design category of Basic. These dwellings are generally older, larger and without specialist design features. Legacy SDA are dwellings intended to accommodate 6 or more long-term residents. Basic SDA is not purpose built (see section 4.2.6). It is also dominated by larger dwellings – of the 2,214 SDA dwellings in the Basic design category, nearly half (43 per cent) are 4 or 5-resident group homes.[1499] As a consequence, ageing SDA dwellings are often overcrowded and offer limited private personal space. For example, multiple residents may be required to share a bathroom.

While the NDIA has set out a timeframe for ceasing payments to Legacy SDA, with payments to cease following the end of the immediate ten-year period after the property's location transitioned into the NDIS, the same cannot be said for Basic SDA.[1500] More broadly, there is no coordinated plan to redevelop or repurpose ageing SDA and support existing residents to access more suitable and contemporary housing.

4.3.1.   There is a large supply of ageing SDA and only small numbers of residents have transitioned to more contemporary housing options

At 30 June 2023, over a quarter (29 per cent) of all enrolled dwellings were ageing SDA, representing over a third (37 per cent) of all SDA places (Figure 102). The actual number of places is likely to be higher, as the count of places assumes that each Legacy dwelling can only house a maximum of 6 residents.

Figure 102: SDA dwellings and places at 30 June 2023 by whether Legacy, Basic, Existing (excluding Basic and Legacy) or New Build[1501]
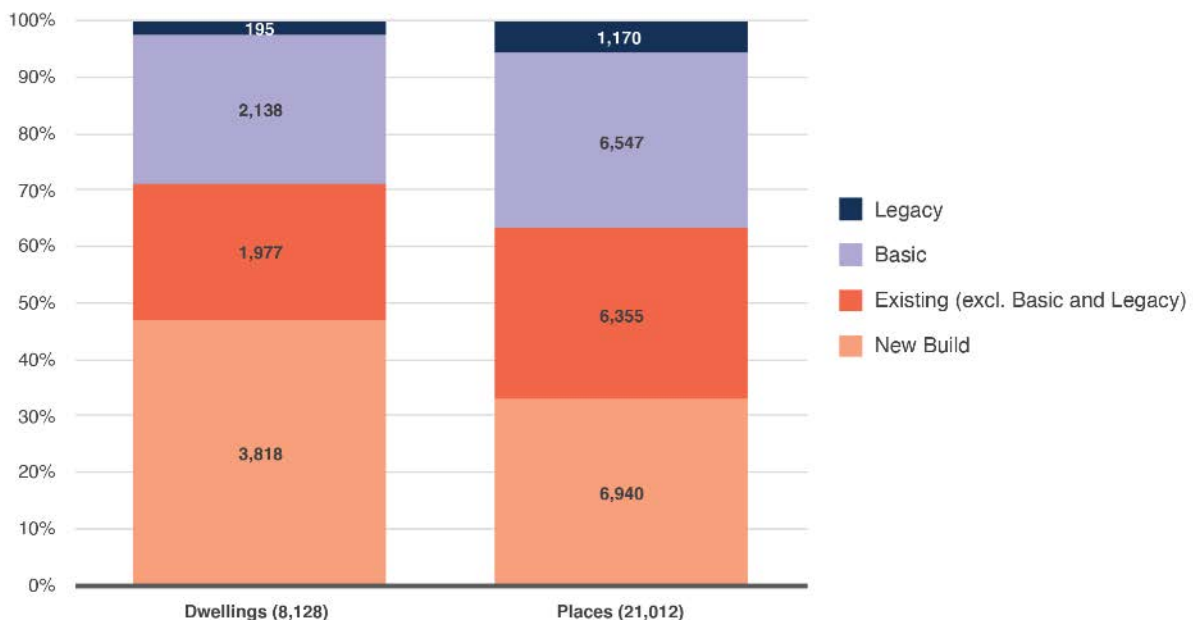
Some states and territories have a much higher share of ageing SDA dwellings than others (Figure 103). with Tasmania, New South Wales and South Australia having a higher share of ageing SDA in their jurisdiction compared to the national distribution.

Figure 103: SDA dwellings at 30 June 2023 by jurisdiction and whether Legacy, Basic, Existing (excluding Basic and Legacy) or New Build[1502]
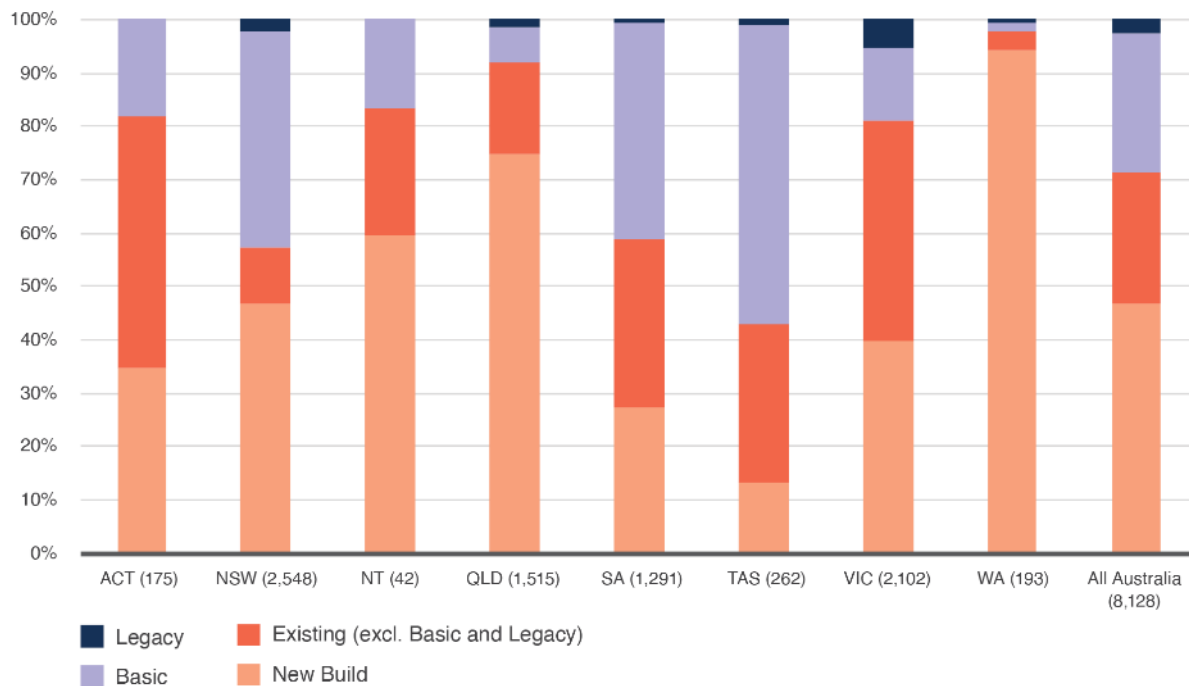
There are significant numbers of participants living in ageing SDA. Of the 11,893 participants who could be exactly address-matched to living in an SDA dwelling at 30 June 2023, almost half (42 per cent, 4,959) lived in ageing SDA dwelling.[1503]

Participants living in ageing SDA share many characteristics.

- Almost all (96 per cent, 4,741) had transitioned into the NDIS from defined Commonwealth, State or Territory specialist disability support programs under the Bilateral Agreements.[1504] As noted earlier in this chapter (see section 3.1.1, Box 44), many transitioned participants have been disadvantaged in their funding allocations and have never undergone a full assessment of their housing and living support needs.
- Two-thirds (69 per cent, 3,427) had a primary disability type of intellectual disability (including Down syndrome) or psychosocial disability.[1505]
- Around 40 per cent were aged 55 or over, with one in ten (11 per cent, 521) over the age of 65.[1506]

Given these characteristics, the housing and living solutions required for this group are likely to be different to those that will suit new participants in the scheme.

The SDA Alliance advised that some of its members had successfully supported participants to move from ageing SDA into more contemporary housing options, or were currently in the process of doing so.[1507] However, they stated that "without future support from governments, this progress will be too slow to meet participant needs in any appropriately timely fashion".[1508]

One SDA provider reported collaborating with a Supported Independent Living (SIL) provider to support six residents to move from a state government owned Legacy dwelling, which the SIL provider was managing on the government's behalf. However, this was a lengthy process – taking 12 months to complete the updated home and living assessments and obtain the increased appropriate funding. They also advised that the dwelling was now sitting empty as the property is no longer habitable or safe to operate – with no plan to utilise the premises or the land.[1509]

4.3.2. Upgrading ageing stock has many challenges

There are many barriers to an effective coordinated process for upgrading or repurposing ageing SDA and supporting those residing in these dwellings to access more contemporary housing.

Fragmented ownership and operation

There are a range of service providers who own and operate ageing SDA, with a significant portion owned by state and territory governments.[1510] These were originally commissioned and built to support individuals accessing specialist disability accommodation programs prior to the commencement of the scheme.[1511] While maintaining ownership of dwellings, some state and territory governments have contracted out their operation. In a roundtable with state and territory officials held in August 2023, officials from some jurisdictions advised that government-owned SDA in their jurisdictions were largely operated by non-government service providers, including community housing providers.[1512] We have heard that these properties were often leased on rolling 2 to 4 year contracts and that these shorter-term arrangements were not conducive to the longer lead times needed for redevelopment planning.[1513]

Other states and territories have registered as government-owned SDA providers and directly manage many of their owned dwellings. This approach is most visible in Victoria, with the Victorian Government-operated SDA provider being the largest SDA provider in the country as measured by total SDA payments in the 2021-22 financial year.[1514] We understand that the Victorian Government has started the process of developing a clear asset strategy for its ageing SDA stock, however, other jurisdictions are less progressed.[1515]

However, not all ageing stock is owned by state and territory governments. At the Review's August 2023 workshop with state and territory officials, it was reported that there were many non-government SDA providers who owned and operated smaller numbers of ageing SDA, sometimes only a single dwelling.[1516] State and territory officials noted that this lack of scale restricted the ability of these smaller SDA providers to gain access to more favourable financing, including access to institutional capital, necessary for redevelopment.[1517]

In the case of SDA owned and operated by SIL providers, uncertainty over whether or not separation of SDA and SIL provisions would be mandated has also acted as a barrier to redevelopment.

Incomplete data

Data held by the NDIA on SDA dwellings overall, including ownership structure, vacancy rates and provider intentions for future usage, is either missing or incomplete. This lack of data was recognised in the recent 2022-23 SDA Pricing Review, which recommended the NDIA undertake a census of all enrolled SDA dwellings.[1518]

The NDIA is also missing dwelling information data for many participants funded for SDA. While there were 23,092 participants with SDA funding in their plan at 30 June 2023, only 10,734 could be exactly address matched to living in an SDA dwelling and therefore can be identified as living in ageing SDA.[1519] A further 2,151 participants could only be approximately address-matched to living in an SDA dwelling and there were another 1,151 participants with evidence of SDA payments being made (suggesting they are residing in an SDA dwelling), but had no address match.[1520] Without an actual address match, information on the type of SDA dwelling these participants reside in is unclear or missing entirely. As a result, the true number of participants living in ageing SDA dwellings is likely to be higher.

Needs, preferences and SDA eligibility of current residents is unclear

Given the shared characteristics of those participants residing in ageing SDA, many will require additional support to express their future housing needs and preferences. However, as noted in section 3.22, such support has been lacking to-date, with these residents particularly disadvantaged.[1521] Our proposed introduction of Housing and Living Navigators (see Action 8.2) and the prioritisation of transitioned participants for reassessment (see section 3.2.5) should assist in overcoming this challenge.

We have also heard that some participants living in ageing SDA can be reluctant to explore options to move, as they are fearful of losing their SDA entitlement through reassessment.[1522] As noted earlier, not all participants living in ageing SDA have SDA funding in their plans. At 30 June 2023, there were 633 participants who could be exactly matched to living in an ageing SDA dwelling without SDA funding in their plan.[1523]

The SDA Pricing and Payments Framework provides that participants who transitioned from pre-scheme disability service systems who were residing in "existing supported accommodation" such as group homes and large residential accommodation will be eligible for SDA.[1524] While the Framework goes on to say that this entitlement will need to be confirmed by the NDIA, our understanding is that this has not occurred – creating confusion and fear from participants that they will lose their SDA entitlement if they attempt to move.[1525]

We believe that the NDIA should remove any ambiguity regarding the SDA entitlement of transitioned participants living in ageing SDA. It should affirm their eligibility for a reassessment for a contemporary SDA design. This would give participants the confidence to explore appropriate

housing options, should that be their preference. Offering greater certainty to transitioned participants and undertaking their reassessments will also likely assist in facilitating the redevelopment of ageing stock. Indeed, until reassessment takes place, the SDA design category and dwelling type these participants will be found eligible for—and consequently their funding entitlement—remains unknown. We have heard that this uncertainty has led to hesitation amongst providers, investors and developers to proceed with upgrades or refurbishment of ageing stock.[1526]

Financial sustainability implications

The average annual SDA base price for a participant living in ageing SDA is $8,118.[1527] This compares to an average annual base price of $47,687 for New Build SDA.[1528] Moving participants from ageing SDA and into more contemporary settings will clearly cost more.

> *The average participant only receives enough funding to live in either group homes or older Existing and Legacy stock. Given that payments for Legacy stock cease 5-10 years after enrolment, and that there are currently over 1,600 places in Legacy SDA, the Agency will need to increase funding amounts for a large proportion of participants to enable them to move into New Build SDA in coming years." – SDA Provider Experience Survey report[1529]*

However, it was always intended that transitioned participants would have a full assessment of their needs after entering the scheme, and the cost of doing so should be reflected in projected scheme costs. The potentially significant benefits of moving to more contemporary stock also needs to be taken into account.

Not all residents living in ageing SDA are funded by the scheme

Many individuals residing in ageing SDA are not supported by the scheme, but instead access the Disability Services for Older Australians (DSOA) Program. DSOA was established on 1 July 2021 to replace the Commonwealth Continuity of Support (CoS) Program, which was made available to individuals accessing pre-scheme specialist disability services who were 65 years or older when the scheme rolled out in their area.[1530]

Ability Roundtable data for the 2021-22 financial year revealed that there were 2,098 DSOA clients residing in ageing stock operated by the service providers who participated in their SIL benchmarking survey.[1531] This can further complicate redevelopment as there is no SDA-equivalent funding available to DSOA clients despite many residing in the same dwelling as participants funded for SDA.[1532] The Review recommends that DSOA cease to operate (see Action 2.12). This means that when DSOA clients become NDIS participants with access to SDA funding, this barrier would be removed. It would also mean that Shared Support Facilitators (see section 3.3) can work across all clients living together in the one house.

Increasing building costs

Building construction costs have increased significantly across Australia in recent years.[1533] Almost all stakeholders who participated in the NDIA's 2022-23 SDA Pricing Review highlighted significant growth in the cost of both building materials and labour.[1534] While these increased costs were

reflected in increases to New Build SDA prices, owners of ageing SDA dwellings have faced these same cost pressures, which have made redevelopment of these assets a less attractive proposition.

Supporting existing residents while building for the future

As noted above, many residents of ageing SDA dwellings are themselves ageing. Like many Australians, some residents are likely to want to age in place and remain connected to their local community.[1535] Additionally, despite not initially having been given a choice as to who they share their home with, there are households where residents have formed close bonds after decades of shared living.[1536] Therefore, any engagement with this group must recognise that choosing to remain in their existing arrangement is just as valid a choice as moving, which should be respected and supported. However, there is an inherent challenge in supporting the needs, preferences and desires of existing residents, whilst ensuring that future SDA stock is suitable for a new generation of participants.

4.3.3. A clear strategy is needed to achieve respectful and timely transition of residents

The array of complex challenges highlighted above speak to a pressing need for a strategy to upgrade or repurpose ageing SDA.

Given the extent to which state and territory governments own and/or operate ageing SDA stock, the issue is best addressed via an intergovernmental strategy. This needs to be led by the NDIA alongside state and territory governments. We note this recommendation was made recently in the 2022-23 SDA Pricing Review, which called for the Australian Government to "work with the states and territories which continue to own SDA stock to develop options and timelines for the refurbishment and/or redevelopment of that stock as New Build SDA".[1537]

The strategy should include the following:

- A reassessment process for working with, and intensively supporting, participants living in ageing stock to explore their housing and living goals, and assessing their needs and eligibility for more contemporary arrangements.

  - The process should take into account the interactions of location and community connection and existing circles of informal supports (noting the proposed flexibility in SDA pricing outlined in section 0 to allow properties in some circumstances to be priced above the price cap).

  - The process should also ensure that participants residing in ageing stock are given timely, equitable and consistent assessments of their housing needs.

- A guarantee that anyone found ineligible for SDA through this process will have their entitlement to SDA grandfathered and receive continuity of SDA arrangements.

  - It should also ensure that where transitioned participants have co-residents with higher support needs (requiring, for example, Fully Accessible or High Physical Support SDA) and they wish to continue to live with them, flexibility in SDA arrangements for this group should be supported,

- Transitioned participants should also get priority access to vacant, pre-existing Improved Liveability SDA stock.

- Clear timetables for upgrading or repurposing stock and for transitioning participants according to the outcomes of the reassessment process.

  - This should take into account the need to intensively support participants through the process of transitioning out of ageing stock, and to respect the wishes of those who wish to stay.

A key part of the strategy should be to commission expert competencies for assessing the housing and living needs of participants residing in these dwellings, combined with active disability representative organisation advocacy support to ensure needs, friendships and community connections are understood and respected. This expertise must include skills and understanding of aging related needs for those with an intellectual disability and take these factors into account when determining SDA requirements and living supports for their future.

To ensure that governments are held to account for the obligations set out in the strategy, it should be embedded within the new Disability Intergovernmental Agreement (Disability IGA) (see Action 20.1) as part of the targeted action plan for housing in Australia's Disability Strategy (see section 4.4).

While this will lead to an increase in scheme costs, there will also be sizeable benefits.

4.3.4. Reducing the bedroom count of ageing SDA dwellings

As noted above, ageing SDA dwellings generally have high bedroom counts. According to NDIA SDA dwelling enrolment data, at 30 June 2023 there were:

- 377 Basic SDA 4-resident group homes
- 584 Basic SDA 5-resident group homes
- 195 Legacy SDA dwellings (6 + residents).[1538]

At 14 September 2023 there were 168 vacancies across these three dwelling types listed on the NDIA's SDA finder tool.[1539] However, as noted in section 4.2.2, this tool only lists vacancies that are voluntarily submitted by providers – meaning the actual number of vacancies in these types of dwellings is likely to be higher.

We have heard that it can be challenging to fill vacancies in ageing SDA and in larger dwellings in particular. Ability Roundtable provider benchmarking data from 2021-22 revealed that ageing stock with four or more bedrooms tended to have high average vacancy lengths.

> *"The data suggests participants living in larger group settings are likely to be an older group of participants who have resided together for longer periods of time. The dwellings (usually 4 -5 bedrooms or more) are older, legacy stock and/or former government operated dwellings which are also typically older stock. This supports the vacancy data where we see less vacancies due to established 'households', however*

> *there are long vacancy lengths as it is more difficult to fill due to household dynamics and outdated and ageing stock." – Ability Roundtable[1540]*

Ability Roundtable identified a range of drivers behind this, including younger participants with SDA funding not wanting to live in an outdated dwelling alongside residents who were in their 50s and 60s with whom they had little in common.[1541] It was also reported that some SIL providers, as a matter of principle, did not want more participants moving into unsuitable housing stock.[1542]

In consultations with several large SIL providers, it was reported that when a participant moved out of an ageing dwelling with four or more bedrooms, the NDIA was unwilling to change the remaining participants' support ratios to reflect the group's smaller size – for example – shifting to a 1:4 support ratio where a vacancy arose in a five-bedroom house. These providers were instead told that it was their responsibility to fill the vacancy, which limited their options. They noted that they could continue supporting the remaining participants with a reduced support budget, but maintaining the same level of support with reduced funding was not viable in the long-term. The alternative was to find another participant who would be the right match for the household, but this was difficult as older stock was not appealing to prospective participants, and accommodating the preferences of a larger sized group was challenging. Sometimes they had to resort to closing a single home and re-locating residents to other homes with vacancies. They emphasised that each of these options resulted in poorer participant outcomes.[1543]

We recommend that the NDIA amend its policies so that when a vacancy occurs in an ageing SDA dwelling that houses more than three participants, the SDA dwelling is able to be re-enrolled at a lower resident count, and living support funding for remaining participants is adjusted to reflect the revised number of residents.

For example, if a vacancy arises in a five-resident Basic SDA group home, the dwelling would be re-enrolled as a four-resident group home and the four participants sharing supports would have their SIL funding adjusted to a 1:4 support ratio. If another participant in the same household departs, then the dwelling would be re-enrolled as a three-bedroom house with the remaining participants having their funding adjusted to a 1:3 support ratio. Should a further vacancy arise, it would be the responsibility of the service provider working with the remaining two participants and/or their supporters to fill the vacancy or find appropriate alternative living arrangements. This process should continue until the intergovernmental strategy for ageing SDA (see Action 9.8) comes into effect.

This change will stop participant households being forced to be disbanded, and will represent a move towards more contemporary arrangements.

The NDIA should also look ahead. Where there are three elderly residents in ageing stock wishing to continue to live together, the NDIA should prioritise working with them to consider alternative, more appropriate accommodation. The alternative accommodation could provide for shared supports on the basis of 1:3 but also allow for more individualised solutions so that any future resident who is younger feels at home, rather than needing to share with much older co-residents with whom they have little in common.

4.3.5. Action & Implementation details

Action 9.8: <u>All Australian governments</u> should agree and implement an intergovernmental strategy for upgrading or repurposing ageing Specialist Disability Accommodation stock owned by states and territories

The strategy should be embedded within the new Disability Intergovernmental Agreement (see Action 20.1) as part of the targeted action plan for Housing in Australia's Disability Strategy (see Action 9.11). The strategy should set out timetables for upgrading or repurposing ageing (Legacy and Basic) Specialist Disability Accommodation stock and transitioning participants to appropriate housing in line with their needs and preferences. The strategy should include sensitively responding to preferences of residents and should be designed in collaboration with residents and their supporters and advocates.

Implementation detail:

- The strategy should include:

  - A reassessment process for working with, and intensively supporting, participants living in ageing stock to explore their housing and living goals, and assess their needs and eligibility for more contemporary arrangements, taking into account the interactions of location and community connection and existing circles of informal supports.

  - A guarantee that anyone found ineligible for SDA through this process should be grandfathered and receive continuity of SDA arrangements.

    o It should also ensure that where transitioned participants have co-residents with higher support needs (requiring, for example, Fully Accessible or High Physical Support SDA) and they wish to continue to live with them, flexibility in SDA arrangements for this group should be supported
    o Transitioned participants should also get priority access to vacant, pre-existing Improved Liveability SDA stock.

  - Clear timetables for upgrading or repurposing stock and for transitioning participants according to the outcomes of the reassessment process, taking into account the need to intensively support participants through this process.

Action 9.9: The <u>National Disability Insurance Agency</u> should amend its change of circumstance and Specialist Disability Accommodation (SDA) policies to reduce the bedroom count of ageing SDA dwellings

National Disability Insurance Agency policies should be amended to reflect that when a participant exits ageing (Legacy and Basic categories) Specialist Disability Accommodation

stock that houses more than three participants, the dwelling is able to be re-enrolled at a lower resident count - down to three residents - and funding for remaining participants is adjusted to reflect revised support ratios. This should reduce the incidence where participants are being encouraged to choose housing that does not meet contemporary standards.

Implementation detail:

- The NDIA should immediately amend its change of circumstance and SDA policies so that when a participant exits ageing SDA stock, which houses more than three participants, funding for remaining residents is adjusted to reflect increased support ratios in line with a lower number of residents in the dwelling — that is, do not seek to fill the vacancy and reduce the number of residents in the dwelling up to a maximum of three residents. The dwelling should also be re-enrolled at a lower maximum resident count.
- This should continue until the strategy for ageing SDA stock (see Action 9.8) has been completed.

4.4. Participants not eligible for SDA face difficulties accessing accommodation

Secure and affordable housing is foundational to the lives of all Australians. The NDIS alone cannot deliver this – all governments have a role to play. Intergovernmental cooperation can ensure that participants who are not eligible for SDA (the vast majority of all participants) are supported in accessing better mainstream housing options.

While it is outside the scope of this Review to deal with the broader housing affordability challenges common to all Australians, including NDIS participants, there are several matters that require a disability-specific response. These include assistance finding appropriate accommodation for participants funded for 24/7 shared living supports, accessibility of the general as well as social housing stock (including the role of the Livable Housing Design Standard in the NCC), and residential tenancy rights for NDIS participants.

4.4.1. Barriers accessing accommodation for people with disability

Only 3.8 per cent of participants had SDA funding in their plan at 30 June 2023. Participants who are not eligible for SDA are often forced to rely on social housing or the private rental market.

Access to appropriate housing is often difficult for people with disability, even if they have secured the support they need to live independently. Specific barriers vary across housing tenures, and they are all exacerbated by the shortfall in supply of affordable housing facing all Australians. Indeed, a lack of affordable and accessible housing was a key housing challenge identified in submissions.[1544]

Overall, appropriate and affordable housing is out of reach for many people with disability:

- 11 per cent of Australians with disability live in unaffordable housing, defined as spending more than 30 per cent of gross household income on rent or mortgage payments.[1545]
- People living with disability tend to have lower incomes than those without disability and often live alone if not with their families. Within the OECD and European Union countries, on average, around 11 per cent of people with disability spend over 40 per cent of their disposable income on housing costs and are thus considered "overburdened" by housing costs, compared to around 9 per cent of people without disabilities.[1546] Australia is close to the OECD average.

The barriers and enablers of accessing suitable housing are well researched (Figure 104). First Nations people with disability in particular face barriers accessing accommodation, especially for those living in rural and remote areas.[1547]

Figure 101: Access to housing, barriers and enablers by tenure[1548]

Tenure	Barriers	Enablers
Social housing (public and community housing)	People living with their parents or in group homes low priority in housing allocations Shortfall in accessible or adaptable social housing stock	• Nomination by support agencies • Special programs (access outside general waitlist) • Priority housing for those at risk of homelessness • Transitional housing • Purpose-built housing • Home modifications
Private rental	Affordability Discrimination Lack of rental history and references Shortfall in accessible or adaptable private rental stock Shortfall in culturally appropriate housing for First Nations people with disability	• Established relationships with landlords • Understanding landlords • Low-value housing markets • Sharing to reduce costs of housing
Home ownership	Affordability Difficulty accessing finance	• Financial support from family • Sharing • Shared equity • Trust ownership • Home modifications

Social housing

Social housing is intended for people unable to afford or access suitable housing in the private rental market.[1549] Social housing encompasses public housing, State Owned and Managed Indigenous Housing (SOMIH), community housing and Indigenous community housing.[1550] As at June 2022 there were 442,737 social housing dwellings, housing 418,434 households, representing 4.1 per cent of all households in Australia.[1551] Around 36 per cent of social housing households included a person with a disability.[1552]

Many people with disability experience barriers to accessing adequate social housing. Much of the existing stock is not suitably designed or well-located for people with disability. A 2020 study which surveyed over 1,000 people with disability found that the majority of people with mobility restrictions in social housing lived in homes that did not meet their accessibility needs.[1553] In a submission to the Review, the Summer Foundation stated that social housing had "few inherent drivers to foster independence and reduce support needs over time".[1554] Most social housing is also not set up to facilitate sharing of supports – creating challenges for participants funded for shared 24/7 living supports but not for SDA (see section 4.4.2).

Social housing is generally allocated according to need, with general and priority waiting lists. Eligibility for the general waiting list depends on income, household characteristics and assets. Priority waiting list criteria are based on a combination of factors or priority segments, usually encompassing both urgency and severity of housing need. The criteria varies between states and territories.[1555] In general, priority housing is reserved for people experiencing or at immediate risk of homelessness, escaping family violence or living in unsuitable housing, and also considered unable to secure housing in the private sector. People with disability may be included as a priority group in some cases.

Due to the narrow definition of need and the eligibility rules around access to social housing, many people in need of housing are excluded from ever getting housed within the system.[1556] Even where people with disability are prioritised for social housing, the shortage of social housing can result in very long wait times and force people to move away from areas of existing supports and services. As at June 2020, it is estimated that there were around 210,000 households nationally on the social housing waitlist.[1557]

As part of Australia's Disability Strategy (2021-2031) the AIHW has recently begun reporting on the average wait time for people with disability to access social housing.[1558] Currently, data is only available for public housing and SOMIH, where the average wait time was 557 days in 2021-22 (for public housing) and 416 days (for SOMIH).[1559] These wait times have increased compared to the prior year, with the average wait increasing by 144 days (for public housing) and 27 days (for SOMIH).[1560] Other data sources show similar long wait times, with a National Disability Data Asset Pilot study finding nearly 1 in 4 households with disability (22 per cent) had to wait two years or more for public housing.[1561]

These issues were observed by the Convention of the Rights of Persons with Disabilities (CRPD) Committee in its 2019 Concluding Observations on Australia. The Committee expressed concern

about "the lack of appropriate, affordable and accessible social housing, which severely limits the capacity of persons with disabilities to choose their place of residence".[1562]

> *"The NDIS didn't do any assessment and then deemed that I was unsuitable for housing by them. Went back to social housing. It was a bit of a situation where I needed accommodation immediately but they were - offered me a unit that was appropriate for physical disability but not for my psychosocial disability [sic]. They told me to reject that property. I did so. They said I would hear back from them in three weeks. Three years later I still haven't heard back from them. So I'm currently in a private rental which means I can't do a whole lot of modifications to make it accessible for me. So things like the bathroom is inappropriate for someone with a disability but I just have to do it. And then also pay double what I would be paying if I was in NDIS accommodation or social housing. So that's where I'm at. Stuck in the middle, yeah." – Participant* [1563]

While most social housing tenants report benefits from living in social housing, there is evidence to suggest this might not be the case for people with disability living in social housing.[1564] In its *People with disability in Australia 2022* report, the AIHW reported that social housing households that have at least one person with disability are less likely than those without a person with disability to say that their needs are met for:

- modifications for special needs (73 per cent compared with 83 per cent when rated as important)
- ease of access and entry (85 per cent compared with 93 per cent)
- safety and security, whether at home (79 per cent compared with 85 per cent) or in the neighbourhood (73 per cent compared with 81 per cent).[1565]

The *Having a Go* report also found that "participants in public housing are less likely than those in other housing arrangements to report being happy where they live or feeling safe at home (up to - 4.7 per cent)".[1566]

Private rental market

According to a 2018 AIHW report, people with disability aged 64 and under were more likely to rent (40 per cent of people with disability) compared to people without disability (34 per cent).[1567] While many Australians face problems with affordability in the private rental market, people with disability face additional challenges finding rental properties that are affordable, safe and meet their needs.

The private rental market can be prohibitively expensive for people with disability, particularly those who are reliant on income support payments. ABS analysis released in 2021 showed that 75.5 per cent of participants over the age of 16 who were in the scheme at 31 December were receiving a Disability Support Pension (DSP).[1568]

According to Anglicare Australia's 2023 *Rental Affordability Snapshot,* which took a snapshot of all listed rental properties on the website realestate.com.au on 17 March 2023, only 0.14 per cent of

the 45,895 rental properties were affordable and suitable for a single person over the age of 21 on the Disability Support Pension – a total of 66 homes.[1569] This may be overestimating the number of suitable homes, as suitable means appropriate for the number of people or family type – not whether the homes were accessible.[1570] Only four rental properties were affordable for a single person on JobSeeker payment. There were no rentals that were affordable for a person on Youth Allowance.[1571]

> *"If you are on the disability support pension and are single, you can't afford a rental, only the street." – Participant*[1572]

The Australian Government increased Commonwealth Rent Assistance in the 2023-24 Budget in an effort to ease affordability pressures on renters.[1573]

We have heard that very few private rental properties are accessible.[1574]

> *"The private rental market is a disaster for disabled participants. There is nothing to encourage private landlords to make homes accessible. I have had a participant in a wheelchair living for 2 years in a private rental where he can't access the bathroom properly." – Carer*[1575]

People with disability can also face discrimination in the private rental market, either directly on the basis of their disability or indirectly due to other factors such as a lack of rental history of secure income.[1576]

Most jurisdictions have a range of state and territory-funded tenancy support programs to help renters overcome some of these barriers. These cover, for example, assistance with bond payments or utilities concessions. However, a Productivity Commission report found that these are underfunded and fragmented.[1577] The NDIS also funds tenancy support services, but these are limited.

Difficulty modifying homes

There are several barriers to home modifications to make a home more accessible.

A number of submissions have described challenges in obtaining funding from the NDIS for home modifications.[1578] In the 2022-23 financial year, 7,259 participants claimed a payment for home modifications with total payments of around $119 million, which accounted for just 0.3 per cent of total scheme payments.[1579]

There are also challenges with using the funding once it is obtained. For the period 1 October 2022 to 31 March 2023, utilisation of home modifications funding was 74.5 per cent.[1580] Lengthy wait times for modifications to be made once approved, overpriced quotes and fraudulent behaviour have been reported as barriers to utilising funding.[1581] Delays in the approval of home modification quotes have been singled out.[1582]

> *"Wait times in funding approval; up to 2.5 years waiting on outcome of quote request because "still being considered by NDIS'.... that's a long time for a participant to not be*

accessing their home more independently or safely. When funding is approved and we are able to provide the recommended CHM [complex home modifications], it is very rewarding to be able to assist people with increasing their safety and independence within their homes/workplaces." – Home modifications provider[1583]

People living in rental accommodation who need to modify their home face specific challenges, which can be especially stressful and challenging for private renters who have less secure tenure than home owners or people living in social housing.[1584] Many submissions described challenges with getting home modifications for private rentals.[1585] Most commonly, this was because landlords refused to allow such modifications.[1586]

"The private rental market is a disaster for disabled participants. There is nothing to encourage private landlords to make homes accessible. I have had a participant in a wheelchair living for 2 years in a private rental where he can't access the bathroom properly. He could have had home mods funded by ndis, but the landlord said no to modifying anything." – Support Coordinator[1587]

Past reports have noted similar concerns. In a 2022 report, the Productivity Commission observed that it can be difficult to secure permission from property owners to make modifications that may be necessary as rental properties are often inaccessible.[1588]

The NDIS will only fund home modifications if it is considered to be value for money. In determining value for money, the NDIA takes into account whether tenure is secure. The NDIA's Home Modifications Operational Guideline states that minor home modifications (generally under $20,000 involving non-structural changes) will likely be value for money if the participant plans to remain in their current home or has a lease for at least 12-months.[1589]

Complex home modifications, on the other hand, will likely be value for money if the participant plans to remain in the home or has a lease for at least 3 years.[1590] Participants are also required to provide written approval from their landlord for the modifications, including whether the modifications need to be removed at the end of the lease.[1591] Given that nearly all rental agreements are only for 12 months this is an almost impossible hurdle to jump over for most participants. In effect those requiring complex modifications must be in SDA or have to manage without.

There are also difficulties with modifying social housing dwellings. In July 2022 the New South Wales Ombudsman reported on its examination of the experiences of public housing tenants with disability who requested modifications to their properties.[1592] It found there were protracted and unreasonable delays, poor communication, inadequate recordkeeping, poor oversight of contractors and inadequate complaint-handling processes.[1593] As a result, some tenants with disability were forced to live in properties that did not meet their needs and were unsafe.[1594]

We heard that there are gaps and inconsistencies in providing home modifications in social housing, including uncertainty around who is responsible for funding home modifications.[1595] The 2021 Victorian Social Housing Regulation Review examined this issue in its Interim Report and

noted the "ongoing standoff" between community housing providers and the NDIS about who is responsible for modifications.[1596]

The NDIS Rules and Applied Principles and Tables of Support provide that the NDIS is responsible for home modifications in social housing "on a case-by-case basis but not to the extent that it would compromise the responsibility of housing authorities to develop, maintain and refurbish stock that meets the needs of people with disability".[1597] The Operational Guidelines for Home Modifications further explain that social housing providers are responsible for making reasonable adjustments that make properties accessible for people with disability, including minor modifications.[1598] Highly specialised or high cost modifications might be funded by the NDIA, but first they will consider if the housing provider has a more suitable home available or can find a property with another provider. Written agreement from the owner is also needed to modify the home. The NDIS is also not responsible for "ensuring that new publicly-funded housing stock, where the site allows, incorporates Liveable Housing Design features".[1599] This is the responsibility of social housing providers.[1600]

We have also heard of difficulties modifying owner-occupied homes.[1601] Submissions have described issues with providing supporting evidence and reports for home modifications, including the costs of obtaining these reports, and inconsistencies in funding decisions for home modifications by the NDIA.[1602]

An inability to modify one's home – irrespective of the source of the barrier – can impact the ability of participants to live independently and safely at home.[1603] This can also prematurely push people into inappropriate settings such as residential aged care, or towards higher cost services, such as Supported Independent Living (SIL).[1604]

> *"NDIS would be happy to place my son in SIL at a large cost. However, requests for home mods to provide for his independence are not accepted as it is for a family home. If the participant chooses to remain with family and family are willing, then necessary home mods should be made easier to access (rather than a million reports), as this will provide a better outcome for the participant and save money for NDIS." – Anonymous[1605]*

4.4.2. Appropriate and effective housing for participants funded for shared living support but ineligible for SDA

Participants funded for 24/7 shared living supports face particular difficulties accessing suitable and affordable accommodation. At 30 June 2023, there were 12,954 participants with SIL funding in their plan who were not funded for SDA – around 40 per cent of all participants funded for SIL.[1606] The proportion of participants funded for SIL-only supports has remained relatively steady over the past few years (Figure 105).

Figure 105: Number of participants with SIL-only supports and number of participants with both SIL and SDA supports[1607]
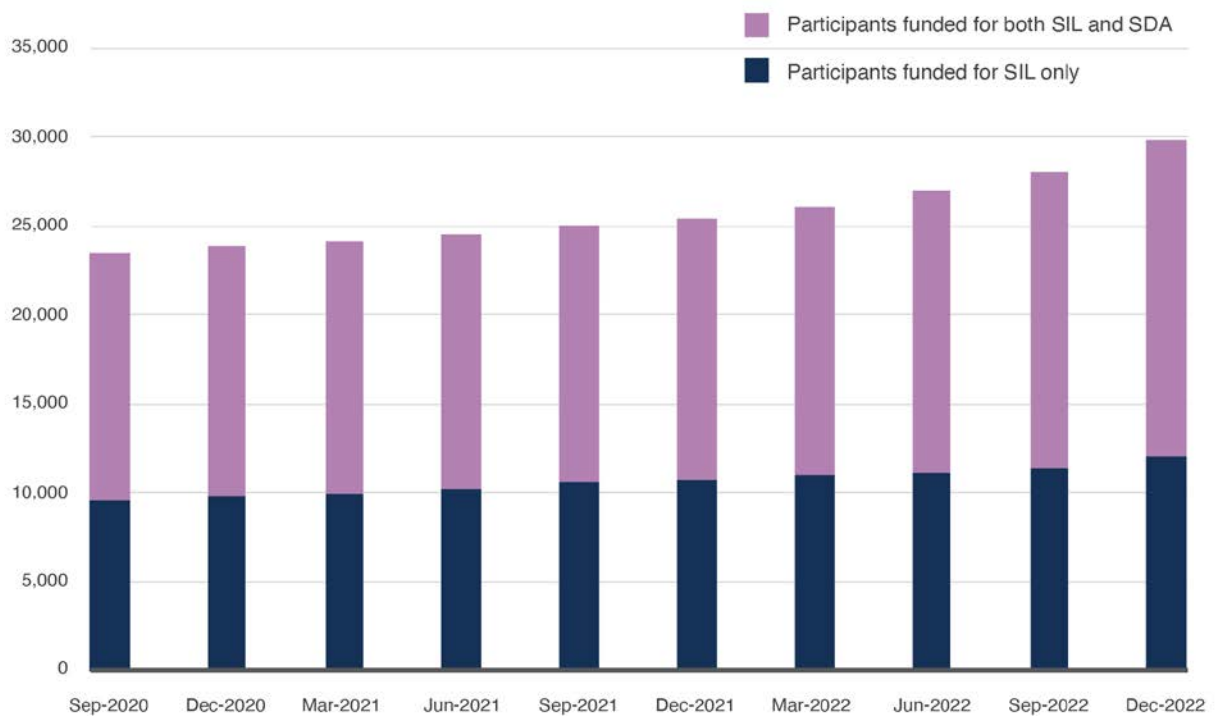
Participants get little support from the NDIS to locate accommodation appropriate for sharing supports. The NDIS has a support item called 'Assistance with Accommodation and Tenancy Obligations', which can be used to fund support to "guide, prompt, or undertake activities to ensure the participant obtains or retains appropriate accommodation".[1608] However, data shows that very few participants access this support. In 2022-23, only 445 participants claimed for this support with an average payment of $1,893.[1609]

Combined with the rental affordability crisis and difficulty accessing social housing (see section 4.4.1), we have heard that participants with SIL supports are ending up in inappropriate accommodation, like closed system SIL homes and boarding houses(such as SRSs).

> *"...many participants are not eligible for either SDA or Individualised Living Options (ILOs) and the only option for people with disability who can't get into mainstream forms of housing, SDA housing or utilise ILOs are only able to access Supported Independent Living SIL) accommodation, and these types of communal living arrangements don't suit everybody and do not always operate in ethical ways."* – Queenslanders with Disability Network[1610]

If participants with 24/7 living support needs are funded on the basis of their supports being shared, we think it is appropriate that the scheme assists them with finding suitable accommodation that facilitates the sharing of that support. Such assistance could take many forms,

ranging from basic assistance and advice in navigating the private rental market, to direct subsidisation of accommodation.

Why subsidise non-SDA accommodation for those with 24/7 support needs?

Given the importance of appropriate housing in promoting good outcomes for participants and the challenge of finding suitable accommodation that facilitates the sharing of supports, we think it is appropriate for the scheme to fund an accommodation subsidy for those who need 24/7 living supports and are funded on the basis of those supports being shared. There are several reasons for this:

- The NDIS directly benefits from participants accessing appropriate housing for their needs, in terms of lower costs and more effective delivery of living supports and other supports. For those with 24/7 living support needs, those cost savings can be substantial.
- Such funding would replace the implicit rental/capital subsidies that are, anecdotally, taking place in SIL homes through cross-subsidisation of rent from SIL packages (see section 2.3.1). This will lead to transparency of that implicit assistance and ensure it is applied fairly. Without some form of rental subsidy, the reality is that many people will either have no choice but to remain in a SIL home or, if structural separation of housing and living support providers were to be enforced outside of SDA, residents would likely be left without an affordable place to live. Anecdotal evidence suggests that many SIL homes are only viable with accommodation costs being cross-subsidised from participants' SIL packages.
- It will also be an enabling reform for the delivery of innovative housing arrangements that foster best-practice delivery of shared living supports, especially when combined with the proposed new Practice Standards for 24/7 Living Supports (see Recommendation 17).

This approach will also explicitly recognise that there are intrinsic capital costs associated with the delivery of 24/7 living supports. For example, if one or more participants in a three-person share house have passive overnight support needs, i.e. the need for sleepover support, then a separate room must be made available for the support worker to sleep in. This is not an optional requirement. Clause 25.7(c) of the Social, Community, Home Care and Disability Services Award, which covers disability support workers, prescribes that an employee performing a sleepover shift "will be provided with a separate room with a bed and clean linen, the use of appropriate facilities (including access to food preparation facilities and staff facilities where these exist)".[1611]

Funding capital costs that are intrinsic to the model of support being delivered is not an unfamiliar concept for the scheme. Indeed, the NDIA already adopts this approach for some supports. Currently, if a participant chooses to access social, economic and community participation supports from a provider delivering them in a facility, then the service provider can claim for both the support costs and an additional separate amount - 'Centre Capital Costs' - which the NDIA describes as paying "for the costs of running and maintaining a facility" for each hour of support delivered in the facility.[1612] The NDIA also recognises there are capital costs in the delivery of Short Term Accommodation and Assistance (STAA), with 2023-24 STAA prices including a support component, plus a capital component of $146.75 per day and a further 'hotel component' of

$59.50 per day, which is described as covering "costs like food, heating, cleaning, etc. associated with the support".[1613]

Options for delivering an accommodation subsidy

We explored several options for delivering an accommodation subsidy to participants funded for shared 24/7 living supports but not eligible for SDA. These included:

- A subsidy delivered directly to non-SDA participants funded for shared supports for use in the private rental market.
- A head lease model for community housing providers (CHPs) to take out long term leases in the private rental market, and rent them out to participants at below-market (subsidised) rents.
- Funding directed to social housing providers to build new social housing stock, or refurbish existing stock, so that it is fit-for-purpose for participants sharing supports.
- Funding directed to building new affordable housing that is appropriate for sharing of supports.
- A subsidy delivered through SDA.

Each of these options have pros and cons. For example, a subsidy given directly to participants to use in the private rental market has the advantage of being portable and therefore giving the participant choice and control. However, we know that people with disability face many barriers accessing suitable accommodation in the private rental market and there is poor security of tenure, which this option does not alleviate. While assisting with affordability, it also does not fix the underlying issue of closed system SIL homes prevailing.

A head lease model operated by CHPs has the advantage that separation of housing and living support providers can be more easily enforced. CHPs also have a great deal of expertise in managing housing for vulnerable groups. On the downside, however, by head leasing properties in the private rental market the security of tenure issues can remain, leading to a lack of stability.[1614] There can also be difficulty sourcing an adequate supply of properties in a tight rental market, particularly those that are accessible, as well as properties where landlords are willing to agree to long-term leases.

Directing funding as capital payments to social housing providers to build or refurbish social housing that is suitable for shared supports has many advantages. It provides residents with security of tenure, as well as stable and affordable rents. Structural separation of housing and living support providers can be enforced, and specific building standards can also be attached. If directed to community (rather than public) housing providers, the skills and expertise of the community housing sector can also be leveraged, as outlined above. However, given the poor track record of governments delivering adequate and suitable social housing, if funding is directed in this way, there is a risk that the supply of accommodation will fall short of intended levels.

Affordable housing shares many of the benefits of social housing but has the disadvantage of tenant contributions being linked to market rents, rather than income, and is therefore more likely to be unaffordable for NDIS participants. Affordable housing also tends to have hidden costs and

complex financing and governance arrangements underpinning it, which makes the subsidy being provided by governments less transparent.[1615]

We see the payment of a subsidy through establishing a new category of SDA as the best way forward. The benefits of this approach are that it:

- Can be brought under the existing policy and regulatory framework for SDA. A new design category can be established, with associated design standards, and providers can be subject to existing Practice Standards for SDA.
- Offers stability and security of tenure (however, further reform to enhance these benefits is warranted – see section 4.4.34.4).
- Allows a market response from investors and providers in an already established market for SDA.
- Keeps control and visibility of funding for housing and living supports together within the NDIA, thus supporting a level of investment in capital that matches demand for shared living supports.

Of course, such an approach would need to be supported by active and improved market stewardship of SDA, as outlined in section 4.2.

With the introduction of this new SDA category, the 'market' for SIL homes would be expected to fall away. As Summer Foundation said in its submission "SIL homes are emerging in the sector, responding to unmet demand from SIL-funded participants who have inadequate or no SDA funding."[1616] But once the new category is introduced, there will be no participants funded for 24/7 living supports not receiving an SDA payment (unless they fall under the specified circumstances for 1:1 funding with no sharing of supports (or only sharing of overnight supports) and are found ineligible for SDA, but we do not expect there will be many, if any, participants in this situation).

And with the recommended strengthening of the SDA Practice Standards to mandate separation of SDA and living support provision, closed system arrangements for those with 24/7 living supports will become a thing of the past (unless a participant, with the support of their Navigator, expressly chooses such an arrangement).

As outlined in Box 48, those who do not require 24/7 living supports might still choose a housing arrangement that is managed by their living support provider. We are not recommending a requirement for separation outside of SDA as it is beyond the scope of this Review. But several of the Review's other proposals will provide added protections, including graduated, risk-proportionate regulation of all providers (see Recommendation 17) and the support of Navigators (see Recommendation 4) and independent Shared Support Facilitators (see Action 8.4).

Accompanying this change should be a decrease in 24/7 living support packages, which are – as outlined above – anecdotally cross-subsiding SIL Home accommodation costs. The introduction of the new category of SDA will explicitly recognise the capital cost of delivering living supports and, therefore, the implicit subsidies currently contained in SIL packages should be removed.

Features of the new SDA category

It is important that the features of the new SDA category are designed in collaboration with participants and the sector. We propose that the details for the new category are designed as part of the recommended review of the SDA categories (see Action 9.4). But there are four key principles that should guide the development of these standards:

> The new category should be lower cost than the other SDA categories, as it would not have such specialised requirements. Current SDA categories have high capital costs because of the many in-built accessibility features and additional space which are costly to build and then are not considered attractive if the houses need to be repurposed. The focus would be on effective sharing of supports, rather than particular accessibility or other specialised design features (as participants who require such features would already be eligible for one of the remaining design categories of SDA). That said, the new category should comply with the NCC Livable Housing Design Standards, to provide for step-less entry that facilitates visits from those with accessibility needs.
>
> Funding of the new category should only cover the additional capital costs associated with providing shared supports safely and effectively. This should be offset by a decrease in any implicit capital subsidies in 24/7 living support packages.
>
> Minimum refurbishment cost requirements for existing properties so that they can be enrolled as New Build (Refurbished) SDA should be far lower than for existing categories. Currently, depending on the building type, design category and whether the dwelling has onsite overnight assistance, an SDA provider must spend between $169,225 and $727,014 on refurbishment to enrol an existing dwelling as New Build (Refurbished) SDA.[1617] A much lower threshold – which could be zero - should be set for the new category to make it easier to enrol existing dwellings.
>
> The design of the new category should not be a reinvention of the Improved Liveability category. The focus of this new category should be on being affordable with standards that appropriately balance the need to facilitate best practice delivery of shared living supports, without adding unnecessarily to cost.

Given that this represents a big shift in the system for delivering SDA and 24/7 living supports, the new shared-living SDA design category should be evaluated within five years to ensure the approach is delivering benefits to participants and the scheme. In doing so, this evaluation should consider opportunities to update the approach to allow participant to 'cash out' their shared-living SDA entitlement to use on compliant properties in the private rental market.

4.4.3. Improved accessibility of the general and social housing stock would reduce pressure on some NDIS-funded supports

Ensuring broader availability of safe, affordable and accessible housing can divert participants away from seeking SIL as a solution to their housing needs.[1618] However, there are a range of issues with the current housing stock. Problems include poor access; unsuitable internal layouts; inadequately designed bathrooms, kitchens and laundries; and a lack of other qualities such as good light and connections to outdoor spaces. Many dwellings are also poorly located in relation to transport,

services and amenities, further limiting participation in the community, particularly around employment.[1619]

The Centre for International Economics estimates that the social cost of the current shortfall of accessible housing in Australia is between $2.2 billion and $2.7 billion per year.[1620] However, other sources indicate this may be an underestimate.[1621]

Progress to increase accessible housing stock has been slow. To date, it is estimated that less than 5 per cent of existing housing stock is suitable for a person with a mobility disability.[1622]

However, there are recent developments that should lead to some improvements. In April 2021, the majority of Building Ministers agreed to include minimum accessibility standards for residential housing and apartments in the National Construction Code.[1623] These were to be based on the Livable Housing Design Guidelines (LHDG) Silver-level standards, which are produced by Livable Housing Australia.[1624] The LHDG, first published in July 2010 by Livable Housing Australia, provides three performance levels or standards: silver, gold and platinum.[1625]

The new standards were adopted into the NCC on 1 May 2023, and are referred to as the Livable Housing Design Standard.[1626] This Standard provides a set of technical provisions which aim to "better meet the needs of the community, including older people and people with mobility limitations".[1627] It requires:

- providing step-free access to the home
- making doorways and hallways easier to use for people with reduced mobility
- providing extra space in the bathroom and toilet
- wall reinforcing in the bathroom and toilet, to make it easier to install grabrails if needed in the future.[1628]

However, not all jurisdictions have signed up to this standard. Each state and territory can determine whether and how the new NCC standards will be applied in their jurisdiction. All jurisdictions, except New South Wales and Western Australia, have committed to adopting the NCC Livable Housing Design Standard. The commencement date varies across jurisdictions:

- The Australian Capital Territory, Northern Territory and Queensland on 1 October 2023
- Victoria on 1 May 2024
- South Australia and Tasmania on 1 October 2024.[1629]

Implementation of the NCC Livable Housing Design Standard will support states and territories with their responsibility to increase the stock of accessible housing.[1630] The adoption of this standard is expected to increase the availability of homes with accessibility features to 50 per cent of Australia's total housing stock by 2050.[1631] More accessible houses will provide NDIS participants with greater choice of appropriate housing and make it easier and more cost effective to make future modifications if needed.

Therefore, we consider that, at a minimum, states and territories that have not already done so should adopt the NCC Livable Housing Design Standard

However, we also recognise that the NCC Livable Housing Design Standard will not solve the undersupply of appropriate housing for participants with greater accessibility needs.[1632] The LHDG Gold Standard is more likely to accommodate people with greater accessibility needs as it requires extra features, such as accessible kitchens, laundries, living rooms and a bedroom on the entry level.[1633]

The Australian Building Codes Board (ABCB) has published a voluntary Livable Housing Design Standard 'Beyond Minimum Standard' which is adapted from the LHDG Gold Level Standard.[1634] The voluntary standard notes that it is not intended for use in designing specialist accommodation and might not accommodate the abilities of all home occupants, but would benefit most.[1635] Some submissions have called for mandatory adoption of these enhanced provisions in the NCC.[1636]

Others have focused on enhancing minimum requirements for social housing, suggesting that all new social housing should be designed and delivered at a level that complies with the ABCB's voluntary Livable Housing Design Standard, or equivalent.[1637]

> *"There needs to be a commitment for all new, government-funded housing to be built at a level that complies with minimum accessibility standards with additional provision for identified people with disability. This would be at the National Construction Code's Livable Housing Design Standard's 'Gold Level' or higher to ensure habitability by a significant proportion of people with physical disability." –*
> *ACT Housing Solutions Innovation Group[1638]*

Most states and territories already require either LHDG Silver Level standards, or equivalents, at a minimum for new public or social housing.[1639] There is also some movement towards building to the LHDG Gold Standard, either as a proportion of social houses constructed, or as features of social housing, such as accessible bathrooms.

In New South Wales, Victoria and Tasmania, new social housing builds are generally constructed to a minimum Silver Level standard and in some circumstances, built to the Gold Level standard.[1640] For example, new social housing in Tasmania is built to the Gold Level for kitchen, laundry and bedrooms and, where possible, at the minimum Gold or Platinum level for specialist housing for people with significant disabilities.[1641] The Australian Capital Territory requires new developments under its Growing and Renewing Public Housing program to be built to the Gold standard to support ageing tenants or tenants with disability.[1642]

We have also heard evidence that private sector building developers are increasingly choosing to adopt LHDG Gold Level Standards, having identified the demand and increased market share that these homes attract.[1643] However, this is not occurring in a way that guarantees practical and reliable accessibility of dwellings.[1644]

There are costs associated with ensuring that housing is more accessible. The Centre for International Economics prepared a Regulation Impact Statement (RIS) for the ABCB examining the costs and benefits of including accessibility standards in the NCC, based on the LHDG, which could apply to the construction of new residential housing.[1645] It estimated that making dwellings more

accessible could cost, per dwelling, between $3,874 for a separate house at the Silver Level Standard, to $37,742 for an apartment at Gold+ Level Standard, depending on the level of accessibility sought.[1646] The RIS concluded:

> *"Although a lack of accessible housing imposes a significant and growing cost on the community (incurred mostly by people with disability and older people)... regulatory options to amend the NCC for all new houses and apartments based on Silver, Gold and Gold+ impose costs that outweigh the benefits." – Regulation Impact Statement*[1647]

However, the Melbourne Disability Institute criticised the cost-benefit methodology for failing to adequately take into account important qualitative factors, including the social benefits of greater accessible housing, while accounting for all costs.[1648] The Melbourne Disability Institute disagreed with the conclusions in the RIS, finding both Silver and Gold standards to be cost-effective.[1649]

There are undisputed benefits for people with disability, and the ageing population, from moving to housing built at the Gold standard in terms of accessibility and greater choice in appropriate housing. Building to the Gold standard would also likely reduce NDIS costs, as better housing can reduce the cost of delivering living supports and enhance good outcomes, and result in less homes that need modification. However, there are also economy-wide costs of moving to Gold including higher build cost which places upwards pressure on prices, and can hold back new housing supply, which can in turn lead to further upwards pressure on prices. These costs affect all Australians, including people with disability.

We are calling for further detailed work on the costs and benefits of moving to gold-level equivalent standards for all new housing. This should include looking at to what extent building costs decline over time as gold-type fit outs become standard, and the costs of retrofitting existing properties to a gold level standard.

As discussed above, a high proportion of people with disability live in social housing, or are on a waitlist for social housing, yet most social housing is not suitably designed for people with accessibility needs. In considering the merit of adopting minimum Gold level standards for social housing, we note that the Silver standard generally still requires substantial modification to a dwelling before it is accessible to a person with disability with mobility restrictions. For this reason, and because the higher cost of building to Gold Standards or equivalent in social housing are borne by governments, and not the private sector, we consider that all new social housing should be built to LHDG Gold level or equivalent.

4.4.4. Improving residential tenancy rights is essential

There is inconsistency in the residential rights of participants living in SDA and SIL homes, compared to others. Although SDA and SIL providers are regulated by the NDIS Commission under the NDIS Act and the NDIS rules, states and territories remain responsible for the residential tenancy rights of people living in SDA and SIL homes.[1650]

In general, participants living in SDA, SIL homes and other supported accommodation settings fall outside the scope of Residential Tenancy Acts in most jurisdictions (see Box 49). To date, Victoria is the only state to enact significant reforms to strengthen protections for SDA residents.[1651] Other states and territories do not contain specific provisions relating to tenancy rights in SDA or supported living arrangements such as SIL homes.

Box 49: Residential tenancy rights for SDA and SIL Homes across jurisdictions

In most jurisdictions, people in SDA and SIL accommodation arrangements are not explicitly recognised under residential tenancy legislation. For example, in New South Wales, the *Residential Tenancies Act 2010* (NSW) specifically excludes occupants of shared accommodation models unless all the occupants have signed a residential tenancy agreement and are therefore co-tenants of the one lease.[1652] Where residents of shared accommodation do not collectively sign a residential tenancy agreement, they are considered only occupiers under the Act and do not have tenancy rights under the Act.[1653] A person living in accommodation as the sole occupant with living support funded by the NDIS may have residency rights under the RTA if a residential tenancy agreement is signed.[1654] This means that people in households with multiple residents in SDA or SIL homes generally fall outside the scope of the *Residential Tenancies Act 2010* (NSW).[1655]

In 2019, Part 12A of the *Residential Tenancies Act 1997* (Vic) came into effect to ensure that people living in an SDA were afforded at least the same residential tenancy rights as those in the private rental market.[1656] Part 12A provides additional protections for people with disability living in SDA and sets out specific provisions concerning rental payments, utility and other charges, as well as the conditions of premises, repairs and access to premises, and termination of agreements and evictions.[1657]

In May 2023, Victoria passed new legislation which, among other things, amends the *Residential Tenancies Act 1997* (Vic) and *Disability Act 2006* (Vic) to further enhance the residential rights protections for people with disability.[1658] These amendments will effectively mean that people living in SIL Homes will also be able to enter into Part 12A SDA agreements under the *Residential Tenancies Act 1997* (Vic).[1659] The relevant provisions are expected to commence by July 2024.[1660]

The gaps in residential tenancy rights for people in SDA and SIL homes create additional risks for people living in these settings, and can affect participants' security of tenure. A number of submissions have stressed the need to strengthen tenancy and residential rights.[1661]

> *"Unclear application of state and territory residential tenancy law to SDA tenancies inhibits SDA providers from establishing governance and business models that support tenant choice and control. This presents significant quality and safety risks to participants and increases their vulnerability to abuse and neglect within the home."* – *Summer Foundation*[1662]

Governments should work together to develop a framework for ensuring consistency in residential tenancy rights for participants in SDA. In doing so, they should ensure that those living in legacy SDA homes do not lose their tenancy rights if they remain in those homes after the legacy SDA payments cease. We note the Disability Royal Commission's recommendation that states and territories should adopt the provisions included in the Victorian Residential Tenancies Act to protect residents of SDA — this would be one way to implement consistency.[1663]

The framework developed should form part of the recommended targeted action plan for housing under *Australia's Disability Strategy 2021–2031* outlined in section 4.4.6. This work will complement our call to introduce a new shared-living category of SDA for participants funded for 24/7 living supports on the basis of those supports being shared, which will result in less people living in SIL Homes (see Action 9.10).

There is also the issue of security of tenure in the private rental market for people with disability. As noted above, short lease times make it harder for people with disability to secure funding for home modifications. It can also lead to a lack of stability in housing and poorer outcomes. It is outside the scope of this review to consider reforms to broader residential tenancy laws and regulations. But we note the Disability Royal Commission's recommendation to replace landlords' 'no grounds' termination rights with 'reasonable grounds', as currently occurs in Victoria, Queensland and Tasmania.[1664] We also note that any changes to tenancy laws (for example, to increase minimum lease periods for NDIS participants) have costs as well as benefits. Renters benefit from greater security of tenure, but they also increase costs and risks for landlords, leading to unintended consequences for renters, including higher rents and risks of discrimination.[1665]

4.4.5. More of the right types of social housing is needed

Across Australia, the supply of social housing is not keeping up with demand. There has been little change in the stock of social housing in the last decade and the proportion of households who live in social housing has seen a steady decline in recent years, dropping from 4.8 per cent in 2011 to 4.1 per cent in 2022.[1666] In a 2023 report, the Australian Housing and Urban Research Institute (AHURI) estimated an additional 942,000 social and affordable dwellings will need to be constructed by 2041 in order to satisfy current unmet and projected future demand for social and affordable housing.[1667]

In recent years, governments across Australia have implemented measures to increase the supply of social and affordable housing.

The Australian Government provides support for social housing through the National Housing and Homelessness Agreement and, for community housing, through Housing Australia (previously called the National Housing Finance and Investment Corporation). The Housing Australia Future Fund, the National Housing Accord and the Social Housing Accelerator also have a key role in improving supply of social housing (see Box 50).[1668].

Box 50: Key agreements and initiatives concerning social housing include:

- The **National Housing and Homelessness Agreement** is a housing and homelessness funding agreement between the Commonwealth and states and territories. It commenced on 1 July 2018. Under the Agreement, the Australian Government has provided around $1.6 billion each year to states and territories to support them to deliver on their housing and homelessness services and programs.[1669] The Agreement also requires states and territories to have a publicly available housing strategy that "includes planned or expected levels of social housing" and "details how the State will contribute to the housing priority policy areas" which includes social housing.[1670] The Agreement has been extended by one year to 30 June 2024, to allow for the development of the new arrangements, in consultation with the National Housing Supply and Affordability Council and states and territories.[1671]

- A **National Housing and Homelessness Plan** is being developed by the Australian Government in close collaboration with state and territory governments. This will be a 10-year strategy setting out a shared vision across all levels of government to inform future housing and homelessness policy in Australia, with key short, medium and longer term reforms needed to address housing challenges.[1672] To inform the development of the Plan, the Australian Government held public consultations and released an issues paper, with the consultation and submissions period closing on 20 October 2023.[1673]

- A **Social Housing Accelerator** payment of $2 billion to deliver thousands of new social housing dwellings. All funding will be committed by states and territories within two years ending 30 June 2025. States and territories have some flexibility in how they permanently boost social housing stock including new builds, expanding programs, and renovating or refurbishing existing but uninhabitable stock.[1674]

- The **Housing Australia Future Fund** to help build 30,000 new social and affordable housing properties in its first five years.[1675] The *Housing Australia Future Fund Act 2023* (Cth) establishes the Housing Australia Future Fund and was assented to on 28 September 2023.[1676]

- The **National Housing Supply and Affordability Council** to advise the Australian Government on matters relating to improving housing supply and affordability including in relation to social housing. The National Housing Supply and Affordability Council is established under the *National Housing Supply and Affordability Council Act 2023* (Cth) which commences on 27 December 2023.[1677] An interim National Housing Supply and Affordability Council was established in January 2023.[1678]

- The expansion of the remit of the **National Housing Infrastructure Facility** to provide concessional loans and grants for new social and affordable housing to deploy up to $575 million to accelerate the supply of social and affordable housing.[1679]

- The 2022 **National Housing Accord** brings together all levels of government, investors, and the residential development, building and construction sector, setting an initial,

aspirational target of delivering 1 million new well-located affordable dwellings over 5 years from 2024.[1680] In August 2023, National Cabinet agreed to a new national target to build 1.2 million new affordable dwellings over five years from 1 July 2024, an additional 200,000 new homes above the target agreed by states and territories in 2022.[1681]

Although people with disability are more likely to live in social housing compared to people without disability, there is limited recognition of people with disability as a national priority cohort for social housing across these initiatives. For example, the National Housing and Homelessness Agreement identifies a range of national priority cohorts, including women and children affected by family and domestic violence, children and young people, First Nations people, people experiencing repeated homelessness, people exiting institutions and care into homelessness, and older people. However, it does not specifically refer to people with disability (although they may fall within one or more of the priority cohorts).[1682]

State and territory governments have also developed housing plans and strategies and announced plans to build more social housing.[1683] In some cases, this includes a focus on suitable housing for people with disability. For example, the Victorian Government has invested $5.3 billion in the Big Housing Build to deliver new social housing that is required to meet, at a minimum, the Silver standard from the Livable Housing Design Guidelines, with five per cent of the houses constructed also having "a high level of physical accessibility … including accessible kitchens, bathrooms and storage".[1684]

A reoccurring theme from submissions has been the need for more appropriate social housing for people with disability not eligible for SDA.[1685] The CRPD Committee has also called for an increase in the range, affordability and accessibility of public and social housing for people with disability.[1686]

> "Undoubtedly, there is also a broader role for governments in increasing the supply of accessible affordable dwellings, particularly in the current national housing and rental crisis. The full implementation of the new National Construction Code (NCC) Livable Housing Design Standard will assist in achieving this outcome. But this must occur in tandem with, and not be allowed to supplant, new government investments to address the acute unmet disability housing needs across the country. Given that less than four per cent of NDIS participants currently have an SDA budget in their plan, disability housing cannot be dismissed as something that is only relevant within the Scheme. It is essential that mainstream housing policies also address this shortfall, including through the proposed Housing Australia Future Fund (HAFF)." – JFA Purple Orange[1687]

> "The NDIA holds data on the housing and support needs of participants who are not eligible for SDA. This should be shared with state and territory governments to enable the development of accessible non-SDA housing, particularly social and public

housing. This will improve housing options and ensure accessibility for people with disability." – Summer Foundation[1688]

We believe there should be targets for new social housing builds that meet the needs of people with disability not eligible for SDA. This is consistent with the Productivity Commission's findings in its 2022 review of the National Housing and Homelessness Agreement, which suggested that social housing should be targeted to people most at risk of long-term homelessness and people who are unable to access and sustain affordable and appropriate housing in the private market.[1689] These targets should form part of the targeted action plan for Housing under Australia's Disability Strategy, proposed in this review (see section 4.4.6)

There is also a need for a dedicated plan outlining an approach to upgrading existing social housing stock so that it can be suitably modified for people with disability. Greater clarity on the responsibilities around funding of home modifications in social housing is also needed.

We acknowledge the work underway with the National Housing and Homelessness Plan and the associated issues paper which includes a question around how social housing could better support people with complex needs, including people with disability.[1690] It is important that this Plan, as well as the National Housing and Homelessness Agreement, is linked to the proposed targeted action plan under Australia's Disability Strategy (see section 4.4.6).

4.4.6. Intergovernmental cooperation will ensure a coordinated and targeted approach to delivering good housing outcomes for people with disability

All governments have a role to play to ensure that appropriate, secure and affordable housing is available to all Australians. The NDIS alone cannot deliver this. Intergovernmental cooperation is essential to ensure that participants who are not eligible for SDA, the vast majority of participants, are supported in accessing better mainstream housing options. But to date, progress has been limited.

> *While Australia's Housing Agreement, Disability Strategy and National Disability Insurance Scheme all share an aspiration for equitable access to housing for people with disability, it is not translating into better housing for many. – MC Two Pty Ltd[1691]*

In August 2023, the Department of Social Services released an issues paper for the development of the National Housing and Homelessness Plan. In it, it noted that there is strong evidence that many disadvantaged and vulnerable people experience individual and complex challenges accessing housing, including people with disability.[1692] It noted that the specific needs of some of these groups are already the focus of national strategies, such as *Australia's Disability Strategy 2021–2031*.[1693]

Australia's Disability Strategy 2021–2031 includes an Outcome Area for Inclusive Homes and Communities. This includes policy priorities to increase the availability of affordable housing, and to ensure housing is accessible and people with disability have choice and control about where they

live, who they live with, and who comes into their home.[1694] There are also key outcomes and measures for each policy priority.[1695]

The Strategy also includes targeted action plans, which are endorsed by Disability Reform Ministers when additional targeted and coordinated actions by governments are required to improve outcomes. Plans are commissioned for one to three years and include specific actions that the Australian, State and Territory Governments each agree to undertake, with progress under the plan reported annually.[1696] Although the Strategy currently has five targeted action plans covering employment, community attitudes, early childhood, safety and emergency management, there is no plan for housing.

A housing outcome area alone is not enough to ensure a coordinated, holistic approach across all levels of government towards improving housing outcomes for people with disability. A targeted housing action plan is needed as part of the *Australia's Disability Strategy 2021–2031*, and this should be integrated with the National Housing and Homelessness Agreement and the National Housing and Homelessness Plan (see also chapter 6). This position was put forward in submissions to our Review.[1697] It also aligns with the Productivity Commission's review of the National Housing and Homelessness Agreement, which recommended that the Australian, state and territory governments should commission a targeted action plan for housing under the Strategy to improve the availability of affordable and accessible housing for people with disability.[1698]

We believe that all Australian governments should agree and publish a targeted action plan for housing under *Australia's Disability Strategy 2021–2031*. The action plan should be developed collaboratively across states and territories and should link to the National Housing and Homelessness Agreement and the National Housing Plan. The action plan should include:

- A commitment for all remaining jurisdictions to sign up to the Livable Housing Design Standards, and that further work on examining the costs and benefits of moving to Gold-level or equivalent standards for all new housing is completed by the end of 2025.
- Clear and measurable actions from each state and territory government for improving and increasing the accessibility and suitability of social housing stock for people with disability and a requirement to build all new social housing to Gold level LHDG or equivalent.
- A framework to ensure consistency in residential tenancy rights for participants in SDA.
- The intergovernmental strategy for ageing SDA stock (see Action 9.10).
- Targets for new social housing builds that meet the needs of people with disability; a plan for upgrading social housing stock so that it can be suitably modified for people with disability; and greater clarity on the responsibility of funding of home modifications in social housing.

As outlined in chapter 6, Australia's Disability Strategy has performed poorly in terms of governance arrangements and reporting requirements. We therefore recommend that Australia's Disability Strategy sit under the new Disability Intergovernmental Agreement (see Action 20.1). The Disability Outcomes Council and the Disability Advisory Council will monitor and assess performance of governments across the elements of the Intergovernmental Agreement and Disability Support Outcomes Framework, including Australia's Disability Strategy (see

Recommendations 20.3 and 20.5). This will help ensure that governments are held to account for the responsibilities set out in the Strategy.

4.4.7. Action & Implementation Details

Action 9.10: The National Disability Insurance Agency should introduce a new Specialist Disability Accommodation (SDA) category for participants funded for shared living supports but not eligible for existing categories of SDA.

A new shared-living category should be designed with participants and the sector to enable the delivery of best-practice and cost-effective supports for participants funded for shared housing and living supports. Funding of the new category should only cover the additional capital costs associated with providing shared supports safely and effectively. This should be offset by a decrease in any implicit capital subsidies in Supported Independent Living (SIL) packages. This should enable broader reforms for delivery of best-practice housing settings for shared living and reduce the cost of living supports over time. This would also ensure a more transparent allocation of funding for the capital component of shared living supports, strengthen safeguarding and secure a transition away from closed-system SIL only housing arrangements.

Implementation detail

- The NDIA should work with participants and the sector to design a new category of SDA for the purpose of sharing living supports. This process should form part of the recommended review of the SDA design categories (see Action 9.4).

  - The focus should be on the design of dwellings that enable the effective delivery of shared supports.

  - It should not prescribe the specialised design features of other SDA categories, because these are not necessary for the target cohort. This will help to keep it lower cost and ensure affordability. However, it should comply with the NCC Livable Housing Design Standards, to facilitate visits from those with accessibility needs.

  - Funding of the new category should only cover the additional capital costs associated with providing shared supports safely and effectively. This should be offset by a decrease in any implicit capital subsidies in 24/7 living support packages.

  - Minimum refurbishment cost requirements for existing properties so that they can be enrolled as New Build (Refurbished) SDA should be far lower than for existing categories.

- Once the new shared-living SDA category is designed, it should be implemented and any required changes to the SDA Rules put into place.
- The new shared-living SDA design category should be evaluated within five years to ensure the approach is delivering benefits to participants and the scheme. This evaluation

should consider opportunities to update the approach to allow participant to 'cash out' their shared-living SDA to use on compliant properties in the private rental market.

Action 9.11: <u>All Australian governments</u> should agree and publish a targeted action plan for housing under Australia's Disability Strategy

The action plan should be developed by jurisdictions and include measurable actions from each state and territory government for improving the suitability of social housing stock for people with disability. This should include a requirement to build all new social housing to gold level Livable Housing Design Guidelines or equivalent. The action plan should ensure consistency in residential tenancy and occupancy rights for participants in Specialist Disability Accommodation (SDA) and include a commitment for all remaining jurisdictions to sign up to the Livable Housing Design Standards in the National Construction Code. It should also be linked to the National Housing and Homelessness Agreement and the National Housing Plan.

Implementation detail:

- The targeted action plan should be released by the end of 2024 as part of the new Disability Intergovernmental Agreement (see Action 20.1) and should include:

  - A commitment that all remaining states immediately sign up to the NCC Liveable Housing Design Standards, and that further work on the costs and benefits of moving to gold-level equivalent standards for all new housing is completed by the end of 2025.

  - A framework for ensuring consistency in residential tenancy rights for participants in SDA , including provisions to ensure that those living in legacy SDA homes do not lose their tenancy rights if they remain in those homes after the legacy SDA payments cease.

  - The intergovernmental strategy for ageing SDA stock (see Action 9.8).

  - Targets for new disability-specific social housing builds; a plan for upgrading social housing stock so that it can be suitably modified for people with disability; and greater clarity on the responsibility of funding of home modifications in social housing.

Chapter 4: Markets and workforce

1. Key messages

- NDIS markets have transformed the way disability supports are delivered, but they are not yet working for all participants across Australia.
- Not all participants have access to safe and quality supports that meet their needs and preferences, nor have they been effectively supported to exercise choice and control. Providers have also struggled to be responsive to meet the needs of all participants, and gaps exist across a number of NDIS markets.
- A more active, flexible and tailored approach to stewarding NDIS markets is needed. This approach needs to expand beyond just setting price caps.
- Governments need to use a range of market tools and tailor the design of NDIS markets to the specific needs and characteristics of participants, providers, and the nature of supports being delivered.

Accessible, timely and reliable information to improve market functioning and scheme integrity

- Access to reliable and up-to-date information is fundamental for any market to function well. However, participants and providers don't have the information they need to make informed decisions. Governments also don't have sufficient market visibility to effectively monitor and steward NDIS markets, nor to protect scheme integrity.
- So for markets to function well and to protect the integrity of the scheme, more accessible, reliable and timely information is needed for participants, providers and governments. With the new approach to supporting all people with disability to navigate the scheme (see Recommendation 4), investment in the NDIS digital infrastructure should also streamline processes needed to support participants to: find, compare and engage local providers, pay for their supports, and manage their budget.

Payment and pricing frameworks to improve incentives for the delivery of quality supports

- How price caps are set is making it hard for providers to respond to participants' needs, and can create unintended consequences. Current fee-for-service payment approaches may not always align the incentives of providers with the interests of participants and governments.
- A new pricing and payment framework is needed. It should use a range of pricing and payment approaches that reward providers for delivering quality supports to participants. These should be developed with greater transparency, predictability and alignment with the broader care and support sector.

Market monitoring and coordinating NDIS markets

- Attempts to use a more active, flexible and tailored approach to stewarding markets have been hindered by limited visibility of NDIS markets. Limited collaboration between providers have also hampered their ability to coordinate delivery of quality care and supports that are responsive to participants' needs and preferences. A lack of effective market coordination has

meant some NDIS markets have not generated sufficient 'thickness' to function well and deliver outcomes for participants.

- Strengthening access to safe and quality supports for all participants would require governments to undertake more active, evidence-based market monitoring and to use a range of responses flexibly to address identified market challenges. This should include: new matching tools, setting up provider panels, and establishing transparent provider of last resort arrangements to ensure participants continue to have access to critical supports should markets fail.

Access to supports for First Nations communities and all participants in remote communities

- Improving outcomes for First Nations participants require equitable, accessible, culturally informed NDIS supports that take into account the strengths of First Nations communities, their rights as Indigenous peoples, and concepts of disability, care and kin. Yet, across Australia, First Nations participants have limited access to culturally appropriate supports.

- Challenges to delivering supports and services to remote and very remote communities are not unique to the scheme, but persistent market gaps remain despite efforts to overcome these challenges. In some of these communities, it can be even more difficult for participants to access culturally safe supports.

- When placed-based and community-driven, alternative commissioning could help the NDIS to deliver more culturally informed, equitable and sustainable supports for First Nations communities across Australia and for all participants in remote communities. These should build on the strengths of local communities, improve outcomes for participants and drive a more sustainable care and support sector over time. Ongoing, meaningful and on-the-ground partnerships with First Nations representatives, communities and participants will be key to success. Time will be needed to build trust and relationships with these communities.

A responsive workforce that delivers quality supports

- The effectiveness and sustainability of the scheme depends on having a responsive and supportive workforce, now and into the future. To deliver quality supports, the workforce needs to have sufficient size and capability with appropriate attitudes to support people with disability as part of the broader care and support sector. However, care and support jobs can be short term, with variable hours, high turnover, poor conditions and poor career prospects. A relatively high share of workers have multiple jobs and employers face little incentive to upskill their workers.

- Meeting the future workforce needs require joint and ongoing action across the care and support sector. There needs to be new ways to attract, keep and train workers, and pathways into the sector should be more targeted and flexible. Governments will also need to work together to better plan for future workforce needs, to identify and address workforce issues, and to drive continuous improvement in the broader care and support sector.

2. A more active, flexible and tailored approach to market stewardship

- The scheme aims to empower participants with more choice and control over what services they receive in using a market-based approach. When NDIS markets function well, participants have more say over who they get services from. By engaging directly with their chosen providers, participants can also have more control over what and how services are delivered, and what prices they would pay. In this way, providers can receive signals from participants about what supports they need and value. When markets are designed well, providers should have the flexibility to respond and innovate in delivering supports that best meet participants' needs and preferences.

- However, NDIS markets are not yet working for all participants in across Australia.

  - A lack of coordination and collaboration has seen some participants face persistent service gaps (including those in remote and First Nations communities) as well as a loss of social capital.

  - Poor market outcomes are being driven by a lack of accessible and timely information, coupled with difficulties in navigating and coordinating supports. Poor market design also means the incentives for providers are not aligned to participants' and governments' interests.

- Governments cannot manage government-funded 'social markets' – such as the NDIS – in the same way as they would manage 'private markets'. For NDIS markets to function well, governments need to use a mix of market-based tools. To date, however, governments have largely relied on price caps to manage NDIS markets.

- To address the challenges participants are facing with NDIS markets today, governments need to take a more active and flexible market stewardship role. A range of market tools should be applied appropriately and scaled up across the NDIS to address persistent market challenges.

- As a basis for all NDIS markets, governments should do more to ensure access to timely and reliable information, put mechanisms in place to facilitate and coordinate markets, and strengthen market rules around quality and safety expectations.

- There is no one-size-fits-all approach to market stewardship. Governments need to tailor market access requirements and pricing and payment approaches to the specific needs and characteristics of participants, providers and the nature of supports being delivered – along with the locations where they are delivered.

2.1. Why have markets to deliver NDIS supports?

The development of NDIS markets is not an end in itself.

Rather, NDIS markets – when well designed and functioning – can be a powerful tool to encourage service providers to be more responsive and effective in achieving outcomes for participants (Figure 06). A market-based approach can allow providers to receive signals from participants

about what supports they value. Providers can compete and have flexibility to innovate and deliver supports that best meet participants' needs and preferences.

Figure 106: Well-designed and functioning NDIS markets ensure the following outcomes
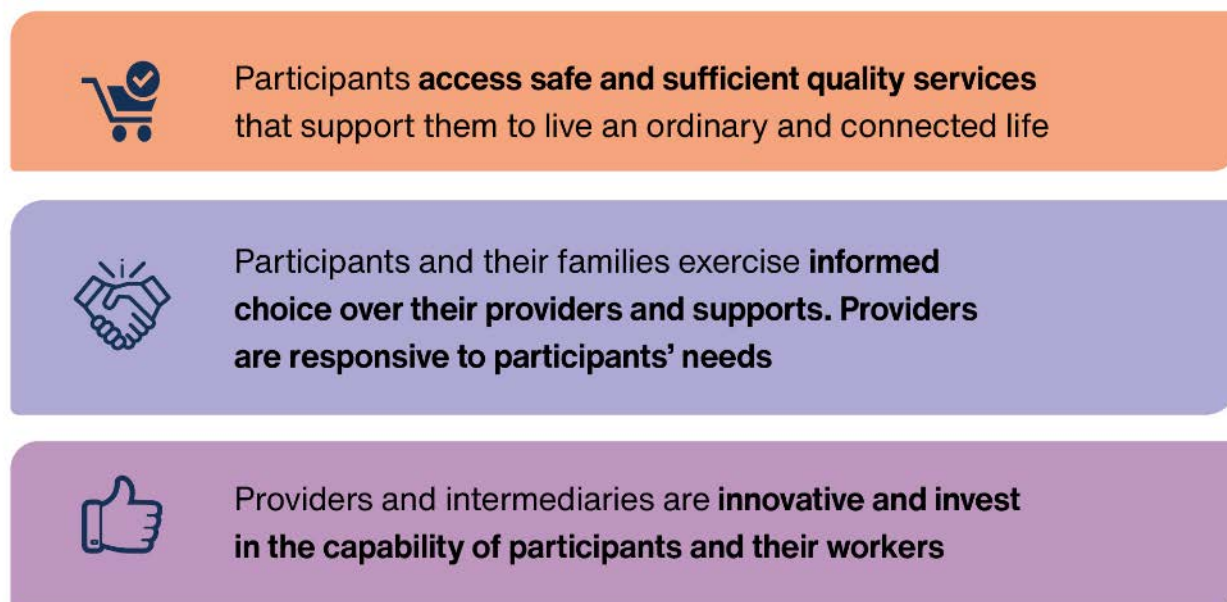
NDIS markets have transformed the way disability supports are delivered.

Prior to the NDIS, Commonwealth, state and territory governments largely determined what services were provided under different disability support programs. People with disability had very little visibility or control over the supports they could access, and who delivered the supports.[1699] Shifting from a government, block-funded model to a market-based model with individualised budgets – where funding follows the participant and not the provider – has enabled participants to have more choice and control over the providers they work with and supports they access.

There is no doubt the shift has achieved a transformational change, and some innovation has emerged in how services are delivered for many NDIS participants.

> *"... a young person with Down's Syndrome who used to receive services from specialist disability providers, being picked up by a bus for people with disabilities and taken to activities that might or might not interest them. When given a budget for services, the person learned how to take public transport, to go the cinema and to buy her favourite meal from McDonald's, which she loved. Best practice was not the achievement of the most efficient allocation of resources within an enterprise, but the meeting of the preferences of the person." – Productivity Commission[1700]*

With this shift also came a significant increase in the scale and diversity of demand for services, along with significant market development. Over 390,000 participants are now receiving disability supports for the first time, as of June 2023.[1701]

2.2. But are NDIS markets designed well? Do they function well for all participants?

Even with the large growth in demand for services, the evolution of NDIS markets over the last decade has not been sufficient to ensure all participants can access quality services, across all locations.

Not all participants have been able to exercise choice and control effectively. Some participants are not supported or empowered to negotiate with providers to access supports that meet their needs and preferences.

> "*A lack of bargaining power and poor incentives for funded support coordinators to optimise supports erodes participant choice and control. Incomplete information and information asymmetries further impede participants' capacity to optimise supports and negotiate prices.*" – National Disability Services[1702]

At the same time, service providers have struggled to be responsive to meet the needs of all participants. Gaps in available supports and services still exist in many locations, which have left many participants without the supports they need.

Some service providers have also reported concerns around financial viability. The National Disability Services *State of the Disability Sector Report 2022* found "... pessimism about the operating conditions facing the non-government disability sector has been increasing for a number of years", with 36 per cent of organisations expecting to make a loss or deficit in 2022-23, up from 23 per cent in 2021-22.[1703]

The challenges faced by participants and service providers are symptomatic of underlying issues in the current one-size-fits-all approach to delivering NDIS supports (Figure 107).

Figure 107: Poor market outcomes for NDIS participants reflect three key underlying issues

A lack of accessible and timely information, coupled with difficulties navigating supports.

Poor market design, where incentives for providers are not well aligned to the interests of participants and governments. Providers are paid based on the quantity of supports rather than quality. Employers are not encouraged to invest in training workers. The performance of providers is not systematically measured and providers have little incentive to compete on price or quality.

A lack of coordination and collaboration in NDIS markets. This has seen some participants face persistent service gaps (including those in remote and First Nations communities). There has been an over-reliance on competition as the only market approach. For some NDIS services, participants and communities, contestable arrangements could better support access while ensuring providers are responsive to the needs of participants.

These poor outcomes in NDIS markets can be, and should be, addressed.

Even when using market-driven service delivery approaches, governments (as market stewards) retain responsibility for ensuring the NDIS, as a whole, delivers outcomes for all participants.

Governments' stewardship roles in the NDIS, and other social services (such as community housing services) are broad. They have roles in supporting informed participant choice, access to quality supports, ongoing service improvements, and ensuring appropriate safeguards are in place (Figure 108).

Figure 108: What is the role of market stewards in the delivery of social services?

Support informed choice
Market stewards give participants the support they need to choose

Access to quality supports
Market stewards ensure supports are suitable, accessible and meet quality standards

Continuous improvements in service quality and effectiveness
Market stewards encourage ongoing improvements and innovation in service provision

Appropriate regulation and safeguards
Market stewards ensure appropriate safeguards are in place for people with disability

Markets for social services are best described as 'social markets' or 'quasi markets'. In a social market, service providers often include not-for-profit and government providers. Choice of provider may be exercised on behalf of consumers, and/or the size of the market is determined in part or fully by the size of government funding.

Governments cannot manage government-funded 'social markets' – such as the NDIS – in the same way as they would manage 'private markets'.

For social markets to function well, governments need to monitor and, when necessary, intervene using a mix of market-based tools. That is, governments need do more than just act as a 'funding body'. As market stewards, governments also need to monitor outcomes and carefully balance considerations of efficiency, effectiveness and equity.

2.2.1   Price regulation remains the primary market tool actively used by governments to help steer NDIS markets.

To date, governments have focused heavily on setting price caps to attract 'efficient' providers to the NDIS market to meet demand.

In social markets, how consumers (in the case of the NDIS, participants) engage and make choices about providers (that is, how they spend their budget) is often not driven by price.

> *"The service provider is often far more than a business to the people who use it. The service provider often provides a [relationship] of care and commitment that may have existed for many years, often through times of considerable difficulty and challenge. Moreover, many agreements commence under circumstances of challenge and difficulty... The conversation with a participant is about whether a provider can help and not about what it costs." – Dr Simon Duffy and Dr Mark Brown, commissioned by Disability Advocacy Network Australia (DANA)[1704]*

Price can take a secondary role in participants' decisions. Participants may not change their provider when prices change. That said, prices of supports are critical for service providers, and affect providers' willingness and ability to supply supports

How participants choose their provider and how well NDIS markets function can be influenced by the rules and processes that determine how NDIS participants and service providers interact with each other (see Box 51).

Box 51: Market design for the NDIS needs more than just prices regulation

Well-functioning NDIS markets depend on detailed rules and processes on how participants and services providers interact with each other.

"Market design turns out to be about details, such as the nature of the transactions in question, the opportunities to conduct transactions outside the market, and the distribution of information." – Alvin E. Roth[1705]

Different rules and processes can make markets work well or poorly.

To function properly, NDIS markets need rules and processes to enable at least three things:

Governments, participants and providers need to be willing to share and disclose relevant information to each other. For example, we have heard some participants are hesitant to tell providers they are an NDIS participant or how much NDIS funding they have due to fear of being charged higher prices.[1706] However, if a provider is unaware that a client is an NDIS participant, they may not meet their safeguarding obligations required under the scheme.

Social markets need to be 'thick' – to bring enough participants and service providers together to ensure both sides are willing to transact.

But too many choices can also be an issue. This 'congestion' needs to be addressed by providing processes and infrastructure to make transacting easier and faster. Indeed, a number of bespoke platform providers have emerged since commencement of the NDIS. In 2021-22, around 16,000 NDIS agency and plan-managed participants used a platform provider.[1707]

A more active and flexible market stewardship approach is needed for the NDIS. This approach needs to expand beyond just setting price caps to look at better ways for participants and providers to connect; create thickness in persistently thin markets; and make it easier and faster to interact in the market.

Governments need more tools in their tool kit.

2.3. Governments need a range of tools to help ensure NDIS markets work for all participants

To achieve the outcomes of well-designed and functioning NDIS markets for participants, governments should monitor NDIS markets and intervene when necessary.

Governments need to use a range of specific tools in order to intervene and ensure NDIS markets function well (Figure 109).

> *"The NDIS system and payments model today was premised on the idea that markets were fundamentally more competitive than they are, and that participants would 'act rationally' to minimise prices for supports. In practice, there are a number of market barriers that prevent the efficient functioning of the market and the 'rational' actions of NDIS participants. Addressing these market barriers will require a combination of pricing and payments reform as well as investment in key enablers to improve market function." – National Disability Services[1708]*

As a basis for all NDIS markets, governments need to do more to ensure access to timely and reliable information; put mechanisms in place to facilitate and coordinate markets; and strengthen market rules around quality and safety expectations.

Beyond this, governments need to take a tailored approach the design of specific NDIS markets. Market design needs to be tailored to the specific needs and characteristics of participants, providers, and the nature of supports being delivered. Key decisions about market design and settings include pricing and payments, and market access.

Box 52: Definitions of key terms used in this chapter

Price settings are the rules and processes around how much sellers of products and services can charge the buyer for the products and services delivered – in NDIS markets, these are the rules and processes around how much can providers charge participants.

Payment approaches similarly set rules and processes around how sellers (or providers) can be paid. Part of this is about:

- Who chooses the provider whom payment goes to – this can be the individual participant, a community or group of participants or the government.
- What support or service is being delivered and how it is paid for – this can include paying for a unit of service (such as an hour or an item), a group or range of activities, supports to be provided over a period of time, or for achieving an outcome.

We typically refer to decisions around price settings and payment approaches collectively as '*pricing and payment approaches*' as these decisions are closely linked.

Market access settings specify additional conditions and processes about who (or which providers) can enter a market to deliver supports and services, which are on top of the broader regulatory requirements.

A more risk-proportionate regulatory model (see Recommendation 17) would set the requirements for all providers to be enrolled or registered to deliver disability supports under the new National Disability Supports Quality and Safeguards Commission. Below are examples of some additional market access settings that could be applied:

Example 1: Government service agreements or deeds for certain supports

- Providers would have to sign up and agree to the terms and conditions for delivering these supports. For example, the terms and conditions could specify that supports must be delivered in line with best practice, or caseloads must not exceed a certain worker to client ratio. Enrolled or registered providers should be able to sign up to the government service agreement or deed (and in doing so, enter the market) at any time.
- Participants should be able to choose any provider who has signed up to the government. Participants should still discuss and agree on the supports and services being delivered and set up their own individual service agreement with the provider.

Example 2: Provider panels for certain supports in a location

- Providers would need to be selected to join the panel in order to deliver certain supports in a location. As part of joining the panel, providers may need to agree to deliver supports in a certain way (such as working with other providers on the panel) or meet additional expectations.
- Participants should be able to choose any provider on the panel, and discuss and agree on the supports and services being delivered. Participants may still need to set up their own individual service agreement with the provider, which should be aligned with the provider panel arrangements.
- Providers would not be able to join or exit the panel at any time – for example, providers would not be able to completely withdraw services in the location at any time they want because it might not be profitable. This should offer participants with greater certainty for access to services. However, there should also be set time periods where the performance of panel providers is reassessed regularly to ensure they deliver outcomes for participants.

Taken together, there will be benefits across the NDIS from moving away from a one-size-fits-all approach towards a more tailored approach to funding and delivering NDIS supports.

Figure 109: Governments should use a range of market tools to more effectively steward NDIS markets to deliver quality supports and, ultimately, outcomes for participants

All NDIS markets need the following to function well:

Information

- **For participants** to make informed choices about using their funding and choosing supports
- **For providers** to make sound decisions about what supports and services they deliver, and how
- **For governments** to monitor and decide when they need to take action, and what action to take

Facilitation and coordination

- Ways for participants and providers (i.e. suppliers) to connect and engage with each other – e.g. online platforms, Navigators
- Actions or responses from governments, as market stewards, for markets to function as intended

Market rules

- Rules that oversee how participants and providers should interact and engage with each other – for example, Practice Standards with quality and safety expectations.

The design of specific NDIS markets needs to consider **needs and characteristics of participants, providers and the nature of supports** being delivered. Decisions about market design and settings would lead to **different funding and delivery approaches.**

Pricing and payments

Who chooses the provider whom the payment goes to?	**Participant**
	Community on behalf of participants
	Government on behalf of participants
What is being delivered, and how is it paid for?	**Fee-for-service payment** for a unit of a support or service
	Activity-based payment for a group or range of supports (or activities)
	Enrolment payment for supports provided over a period of time
	A blend (or mix) of payments including an outcome payment for achieving an outcome or performance measure
How much can be paid for the supports or services?	**No price regulation** for fully self-managed participants
	Price caps to set the maximum amount allowed
	Quotation requirement: price up to the approved quote
	Contracted prices: prices as agreed in contract

Market access

| Who can deliver supports? | **Providers who are registered or enrolled, in line with the risk-proportionate regulatory model** (This is a requirement of all providers, regardless of market access requirements) |

Competitive approaches: Providers compete **in the market** to deliver supports to participants

- **Any provider or preferred providers for capital supports**
- **Service agreement or deeds with government**

Contestable approaches: Providers compete **for the market** to deliver supports for participants

- **Provider panels**
- **Alternative commissioning**
- **Provider of last resort**

Tailoring market design to achieve the best outcomes for participants should be based on an understanding of participants, providers, and the nature of supports in each market (Figure 110).

Figure 110: Designing an effective service delivery approach requires an understanding of the needs and characteristics of participants, supports and providers

Participant characteristics

What capability and support do participants have and need to make informed choices?

How complex are participants' support needs?

Where do participants live, and how do they want to live?

What do participants need to live their lives?

What does success look like for participants?

How will supports help strengthen cultural determinants of living well and address the social determinants of exclusion and disadvantage?

Nature of supports

How important is trust in the relationship between participants and providers?

How important is cultural safety and inclusion in delivering supports?

What are the costs (time and effort) to find or switch providers?

How frequently do participants need the support?

How predictable are the support needs of participants?

Do supports need to be delivered at a specific time of day?

Can multiple supports be bundled together to improve innovation and effectiveness?

Service providers

What is the scope for multiple providers or service options in the market (including economies of scale and scope)?

What is the capacity to monitor provider performance?

What opportunities are there for providers in other sectors?

What barriers or incentives are there to enter, grow, shrink or exit the market?

What workforce capacity and capability is needed (including competency in delivering culturally safe and trauma-informed supports)?

For example, governments may take a different approach to setting pricing and payments approaches (see Section 4) and market access requirements (see Section 5) for:

- **Daily supports**. These supports (particularly for personal care) depend heavily on relationships. Support needs can vary across participants (for example, between children and adults). Typically these are ongoing, need to be delivered face-to-face and, ideally, are provided by workers who are well known by the participant and who deeply understand the participant and their needs.

- **Allied health supports**. These supports depend heavily on trusted relationships and professional opinions and should be based on evidence and best practice. Providers are also likely to have opportunities to deliver in other sectors, such as health and aged care.
- **Capital supports (including assistive technology)**. These supports are often one-off and transactional in nature. Participants and regulators may need professional advice, given the range of alternatives and the often specialised nature of these supports.
- **Communities (including First Nations communities and culturally and linguistically diverse communities)** may share different attitudes, beliefs and values. Trust, cultural safety and trauma-informed approaches will be critical for delivering quality and safe supports.

A fundamental characteristic of many quality NDIS supports is having trusted relationships between participants and their providers and workers.

Building these relationships may take time and this can change how participants engage with providers in the NDIS market – with the choice to switch provider not being a simple decision for participants.

> *"… training new support workers can be a time-consuming and stressful task for participants and their families, and that participants might prefer to stay with a provider that they are not happy with, rather than risk switching to one that is potentially worse. These factors might all limit willingness of participants to switch."* – *Queensland Productivity Commission[1709]*

> *"… consumer choices can depend on a range of cognitive, social, and emotional factors. For example, people tend to stick with the 'default option' even when it is not the best option, or they may face administrative barriers to leaving providers. Staying with the same provider will be a rational response for many people including people with a disability, even if there are higher quality services elsewhere."* – *Advocate[1710]*

The design of NDIS markets, however, currently relies largely on competition between providers and a fee-for-service payment approach.

Competition can offer more choice to participants, and help deliver more responsive supports and better outcomes for participants, as they can choose to leave poor performing providers if they are dissatisfied with the service they receive. Competition relies on participants 'using their feet' to move away from providers who deliver low quality, low value or potentially unsafe services, towards providers who deliver safe, high quality supports that are better value for money. In this way, competition in markets can help achieve the mix of supports and providers that are valued most by participants.

A fully competitive market approach is likely to be less effective where there are high 'switching costs' for participants. As highlighted above, even if participants are dissatisfied with their provider, they may be slow to switch between providers. In this case, competition may not be as effective at driving providers to be responsive to participant preferences.

The Queensland Productivity Commission found the average rate of participants switching providers in Queensland was 12 per cent in 2020.[1711] However, it is difficult to tell what an appropriate benchmark is, as "... low switching rates might simply reflect that consumers are satisfied with their existing service, rather than being indicative of a lack of choice and control".[1712]

What the Queensland Productivity Commission did observe was switching rates and participants' levels of attachment to their providers (that is, the time a participant uses a single provider within a registration group) vary across NDIS registration groups.[1713]

The Queensland Productivity Commission's analysis highlighted that registration groups where switching was low, and attachment was high, included:[1714]

- specialised supported employment, where it was found that a participant-provider relationship was likely to be ongoing and the market was highly concentrated
- Specialised Disability Accommodation (SDA) where a participant was likely to have an ongoing relationship and local markets were concentrated.

In these cases, competition on its own won't be sufficient to ensure participants are able to access quality supports. Additional market tools are needed to realise the benefits of a market-based approach to delivering NDIS supports.

2.4. We have developed a number of practical steps on when and how government should strengthen the NDIS market using these tools

As a basis for all NDIS markets, we have recommended steps to:

- invest in digital infrastructure to enable accessible, timely and reliable information and streamlined processes that strengthen NDIS market functioning and scheme integrity (see Recommendation 10)
- support all people with disability to navigate mainstream, foundational and NDIS service systems – including NDIS markets (see Recommendation 4)
- promote continuous quality improvement through a dedicated quality function in the new National Disability Supports Quality and Safeguards Commission (see Recommendation 12)
- deliver safeguarding that is empowering and tailored to individuals, their service needs and environments (see Recommendation 16)
- develop a new risk-proportionate model for the regulation of providers and workers (see Recommendation 17)
- reduce and eliminate the use of restrictive practices (see Recommendation 18)
- embed effective quality and safeguarding architecture across the entire disability support system (see Recommendation 19).

We have recommended a new pricing and payments framework to improve incentives for providers to deliver quality supports for participants (see Recommendation 11).

Strengthened market monitoring and more tailored market access settings are also needed to address challenges in coordinating the NDIS market (see Recommendation 13). This includes

improving access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements (see Recommendation 14).

Finally, a capable and responsive workforce will underpin the success of all these reforms. We have outlined a number of actions and steps to attract, retain and train a workforce that is responsive to participant needs and delivers quality supports (see Recommendation 15).

2.5. Implementing these reforms requires clear accountabilities across government agencies

"To support effective market stewardship, government departments and other commissioning organisations should: Clarify roles, responsibilities and accountability arrangements …" – Tom Gash, Nehal Panchamia, Sam Sims and Louisa Hotson, UK Institute for Government[1715]

Agencies across the Australian Government have different functions and roles as market stewards.

However, we heard early in the Review about the confusion around the respective roles and responsibilities of different government agencies in stewarding NDIS markets.[1716] No doubt, the lack of clear roles and responsibilities across governments has contributed, in part, to poor market outcomes.

Clarifying these roles will be a critical step in implementing the market stewardship reforms we have recommended.

While the Department of Social Services (DSS) stewards the market by setting market policy, other agencies – including the National Disability Insurance Agency (NDIA) and the new National Disability Supports Quality and Safeguards Commission – have a critical role in providing information and guidance to the market, operationalising policy, monitoring the market and taking action where markets are not functioning well, or as intended (Figure 111). Under our Recommendation 11, the Independent Health and Aged Care Pricing Authority (IHACPA) would also have a new role in advising the Australian Government on pricing. This would strengthen transparency and predictability of pricing and would support greater alignment across the care and support sector (see Section 4).

Figure 111: Recommended NDIS market stewardship functions for Australian Government agencies

Stewards the market by **Setting market policy**

Department of Social Services
- Oversees changes to primary legislation and the broad policy of the scheme
- Coordinates actions across Australian Government and state and territory government agencies to steward the NDIS market
- Works with government agencies to coordinate workforce planning and development across the care and support sector

	Service delivery	Quality and safeguards	Pricing and payments	Scheme integrity
Stewards the market by • **providing information and guidance** • **operationalising policy** through systems and processes • **taking action or intervening** where the market is not functioning well, or as intended	**NDIA** • Informs and educates about the scheme and market (including information to support participant decision-making) • Shares public data and intelligence to the market (including on opportunities and gaps in the market) • Enable connections between participants and providers (e.g. through matching tools) • Sets access and funding approaches for NDIS supports to ensure access to effective, quality supports • Works across government to leverage buying power for better access to supports • Builds partnerships with community to design and roll out service delivery approaches (including alternative commissioning) • Coordinates actions to ensure continuity of access to critical supports where markets fail	**National Disability Supports Quality and Safeguards Commission** • Controls market entry and sets requirements such as provider registration and enrolment, worker screening (with states and territories), behaviour support and restrictive practices (with states and territories) • Informs and educates providers and workers (e.g. about their regulatory obligations) and participants (e.g. their rights and how to raise issues) • Identifies, investigates and responds to complaints, incidents and issues of non-compliance and takes corrective action (e.g. conditions, enforceable undertakings, bans, penalties) • Drives quality through capacity-building of providers, outreach, performance measurement (e.g. communities of practice, good practice guidance) • Works with other regulators and law enforcement to ensure safety and improve market quality • Supports actions to ensure continuity of access to critical supports where markets fail	**IHACPA** • advises on the maximum amounts providers can be paid for delivering supports **NDIA** • Oversees enabling payment infrastructure • Administers payment system (including multiple payment channels), price cap and claiming 'rules'	**NDIA & National Disability Supports Quality and Safeguards Commission** *Shared responsibility* • Refines risk management strategies on an ongoing basis • Sets and refines risk treatments and controls to prevent, detect and respond to non-compliance, fraud and sharp practice (e.g. identity verification, payment controls) • Enforces compliance with scheme integrity 'rules'
Monitors the market (by gathering and sharing data and intelligence) to **inform market actions and interventions**	• Monitors market demand and supply using participant data, payment data and local intelligence (including Navigators)	• Proactively monitors and responds to risks and emerging changes in the market through provider reporting, complaints and other regulatory intelligence	• Monitors and enforces pricing and payment 'rules' • Monitors market responses to price settings • Assists providers with information to compare and benchmark their performance	• Monitors payments, transactions and other intelligence to detect non-compliance, fraud and sharp practice

3. Accessible, timely and reliable information to improve market functioning and scheme integrity

- Access to reliable and up-to-date information is fundamental for any market to function well. However, participants and providers don't have the information they need to make informed decisions in NDIS markets. Current information on what supports can be purchased, what supports are available, and the price and quality of supports is hard to find, access and understand. At times, providers also lack sufficiently detailed, accurate or timely information to be responsive in delivering the supports and services needed by participants.

- Current NDIS processes and systems don't provide governments with sufficient information to enable governments to monitor and steward NDIS markets, and to protect the integrity of the scheme. Incomplete data makes it difficult to know how markets are working and to evaluate what support approaches work best. Governments have also had challenges understanding the nature and scale of non-compliance, sharp practice and fraud across the scheme.

- Investment in the digital infrastructure of the NDIS is needed to provide accessible, reliable and timely information and streamlined processes needed for NDIS markets to function well. Initiatives should include offering better ways to find and compare all locally available providers, and easier and faster ways to pay for supports delivered which would also capture essential data on all transactions. This would enable:

    - participants and their Navigators access to timely and reliable information, better empowering them to act as informed consumers in the NDIS market.

    - providers to have more timely market signals. They would be more responsive and innovative in delivering supports that meet participants' needs and preferences. Providers would also have more market information to benchmark their performance.

    - improved digital inclusion for participants with a range of technologies and channels that deliver a digital experience tailored to the diverse needs of people with disability.

    - digital payment channels, which would make it easier and faster for participants and service providers to engage and transact with each other, and strengthen safeguards for participants and protections for scheme integrity.

- Over time, digital payment systems and the increased support of Navigators in helping participants manage their budgets will reduce the demand for some functions of plan management. Enabling participants to pay all providers – both enrolled and registered providers – through the NDIS payment system should mean Plan Managers no longer "pay the bills". However, the transition to the digital payment system will take time. In the interim, Plan Managers still have an important role to play in supporting prevention, detection and response to non-compliance, sharp practice and fraud. In the longer term, as the digital capabilities of the NDIS grow, plan management will likely need to change significantly.

- Improvements to the NDIS digital landscape should not happen overnight, and should be coordinated well and communicated clearly and early.

Recommendation 10: Invest in digital infrastructure for the NDIS to enable accessible, timely and reliable information and streamlined processes that strengthen NDIS market functioning and scheme integrity

🗐 Legislative change required

- Action 10.1: The <u>Australian Government</u> should develop and fund an easy-to-use centralised online platform that provides information on all locally available supports and services for participants and Navigators.
- Action 10.2: The <u>National Disability Insurance Agency</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should enable better two-way information sharing with third party online platforms to encourage digital innovation that builds on the centralised online platform.
- Action 10.3: The <u>National Disability Insurance Agency</u> should transition to fully electronic payments and improve visibility of NDIS payments.
- Action 10.4: The <u>Australian Government</u> should invest in the underpinning digital infrastructure and capability needed to protect the integrity of the NDIS.
- 🗐 Action 10.5: The <u>Australian Government</u> should develop and implement a clear transition path for existing Plan Managers.
- Action 10.6: The <u>Australian Government</u> should design and roll out an NDIS digital transformation strategy and roadmap to bring together and sequence all initiatives in the NDIS digital landscape.

3.1. More accessible, timely and reliable information is needed for participants and providers to connect and engage effectively

Accessible, up-to-date and reliable information, and feeling safe to share information, is critical for NDIS markets to function well (see Box 51). Information is needed for participants to act as informed consumers and for providers to respond appropriately to what participants need and want. For governments, effective market monitoring and stewardship also relies on having sufficient market visibility and providing clear, timely market signals.

But having too much information and options to choose from can also overwhelm. The scheme needs processes and infrastructure that supports participants to find, choose and engage with providers (see Box 51).

3.1.1 It is difficult for participants to act as informed consumers without accessible, timely and reliable information

Current information available to participants is hard to find, access and understand. There are gaps in the information needed by participants. Often, information can be out-dated, inconsistent or potentially inaccurate in an environment of constantly changing policies, processes and systems.[1717]

"…only 16% of respondents to the benchmark review found it easy to find information on the [NDIS] website, with 37% finding it difficult. The search function was the most common area cited for improvement, followed by simpler language, clearer menus and improved navigation. The ANAO observed limitations with the search function, including lack of facility to filter and refine searches. Participants reported finding information more easily through google searches and provider websites. Glossary and acronyms pages were also out of date." – ANAO Performance Audit of "Effectiveness of the National Disability Insurance Agency's Management of Assistance with Daily Life Supports"

Even when information is available, understanding the complex and changing web of information across different sources requires significant time and effort from participants, their families, carers, and intermediaries (such as Support Coordinators and Plan Managers).

Without accessible, timely and reliable information, it is difficult for participants to make informed decisions about how they use their budget and who they get supports and services from. [1718]

Understanding how an NDIS budget can be used is too confusing and complicated.

"How confusing it is … it baffles me that it is so hard for us to use and access because we have troubles with the things we need to do to get help. No one informs you what things are … [including] what you can use those allocated things for." – Participant[1719]

It can also take a lot of time and effort for participants to find providers.

"[It is] too clumsy for participants and too hard to find providers easily - all the info is dumped into complicated documents and [Australia] wide rather than State based and sector based. How are disabled people and their stressed carers supposed to navigate this?" – Carer[1720]

Finding available local services is unnecessarily difficult (see Box 53). Information on the NDIA and NDIS Quality and Safeguards Commission (NDIS Commission) websites is particularly difficult to navigate, find and understand.[1721]

"But a lot of providers weren't even listed [on the NDIS Provider Finder] … It really wasn't helpful at all and it left me in an absolute panic because I didn't know where to start, what to do." – Extracted participant quote from 'Exercising meaningful choice and control in the NDIS: Why participants use unregistered providers'[1722]

> **Box 53: The NDIS Provider Finder is not fit-for-purpose**
>
> The NDIS Provider Finder tool provides basic information on available, registered providers in a participant's local area.[1723] However, this information can be unreliable and is often not enough for participants to find and choose suitable service providers.[1724]

- The tool does not provide a complete list of all providers delivering NDIS services – it only lists registered NDIS providers.
- Availability of registered providers in a participant's local area can be unreliable – the information is based on providers nominating where their outlets are, and whether they have been paid in the last 3 months.
- Information on what supports and services are offered by the provider is not easy to understand – participants have to make sense of the NDIS registration groups to search for supports. Search results can be incomplete as providers can often deliver other supports that they are not registered to deliver.
- No information is provided by the tool on the prices charged by providers, or quality of supports provided for participants.
- Information on whether the provider has had compliance action taken against them – such as revoking or suspending the provider's registration or banning the provider – is found separately on the NDIS Commission's website (e.g. NDIS Provider Register).

Participants also have little trust in the information shared on providers' websites, advertising and promotions. Many participants, their families and carers rely on word-of-mouth information, advice from others they know and trust, or help from an intermediary (such as a Local Area Coordinator or Support Coordinator) to find and choose services.[1725]

However, a system that is overly reliant on trust and interpersonal information can be problematic.[1726] Given there is no centralised source of accessible, up-to-date and reliable information, participant reliance on trust and word-of-mouth can lead to: [1727]

- **Riskier decision-making.** Information through word-of-mouth is often based on subjective experiences and can be inconsistent. Validity of this information tends to be lower as reliance on this information is based primarily on the perceived trustworthiness of the 'information purveyor', and not the accuracy of the information.
- **Poorer outcomes.** Relying too much on trustworthiness of the person providing the information and not its accuracy may mean that participants could be referred to poor quality providers. These referrals may be made inadvertently by peers where there is no shared understanding of what safe and good supports look like. A lack of accessible and reliable information from a centralised source may also mean participants are unaware that intermediaries (who have conflicted interests) may not be making referrals in the participant's best interests.
- **Greater inequity.** Availability and quality of information relies on people with disability having strong social networks of trusted peers and professionals. This further disadvantages those who do not have extensive social networks or are more socially isolated.

That said, word-of-mouth will always remain an important channel for many people with disability in finding and accessing the supports they need. In many communities, word-of-mouth is

fundamental to their culture and way of being.[1728] However, word-of-mouth channels need to be supported by independent, accessible, timely and reliable information.

Similarly, participants will still need support from families, carers and others in decision-making. Not having a centralised source of accessible, trusted information means that decision-supporters may often spend considerable time and effort to find and understand the information they need to effectively support the participant's decision-making. For formal decision-supporters (such as Local Area Coordinators, Support Coordinators, psychosocial Recovery Coaches and Plan Managers), this can mean less time and effort is focused on supporting the participant to make the best use of their budget or on building their skills and confidence to become more connected to community.

> *"Make things simpler to understand. Less time spent - by NDIS users, providers, carers, staff - on finding and making sense of information - means less time spent on paid and unpaid administration which means more is available overall as part of the NDIS for actual support." – Participant[1729]*

Without an accessible, trusted source of information on available supports and services and what good looks like, many participants, their families and carers are also not supported nor empowered to negotiate with providers to get the supports they need.

> *"Participants are unable to compare providers or negotiate prices where they are not able to access the information they need to make informed decisions." – Women with Disabilities Australia[1730]*

3.1.2 Providers don't have enough information to respond and deliver the supports and services according to participants' needs and wants

Providers also lack sufficiently detailed, accurate or timely information on what supports and services participants need, and where.

The NDIA and DSS do provide analysis and insights into the NDIS market by location, participant demographics and support types.[1731] However, this is often not sufficiently detailed for providers to understand where there are gaps between what existing services (if any) deliver and what participants need and want. Updates to this data by the NDIA and DSS – which can occur every 3 to 12 months – are often infrequent and slow.[1732]

At an individual level, many participants, their families and carers will often need considerable time to feel safe enough in disclosing or revealing information about their needs and their preferences to potential service providers. In fact, we have heard that some self-managing participants do not disclose they are using NDIS funding to service providers because they have concerns that providers may charge higher prices than they would otherwise.[1733]

Information is needed for providers to compare and benchmark their service offerings with others.

Currently, information on who else is delivering what supports and services in the NDIS market is hard to find and compare. When combined with price caps that act more as a 'price anchor' than a 'price ceiling', providers have little incentive to compete on price and quality of supports.

3.1.3 Governments lack sufficient market visibility to effectively monitor and steward the market

Information asymmetries do not just exist between participants and providers but also between governments and the market. To be effective market stewards, governments need sufficient market information and visibility to:

- support participants in making informed choices about their supports and services
- ensure supports are suitable and accessible, and meet quality standards
- encourage ongoing improvement and innovation in services delivered
- ensure appropriate consumer safeguards are in place.

The current financial management methods, and associated policy and system settings, fail to provide governments with sufficient visibility of what is happening in the market to effectively monitor and steward the NDIS market.

Transactions between participants and providers often occur outside of the NDIS information technology (IT) system. Some information on the connections between participants and providers are visible to governments through NDIA-managed service bookings and claims made by registered service providers or via registered plan management providers. However, information gaps still exist.

Governments only have limited visibility of NDIS markets. For self-managed supports, participants are not required to give information on who delivered the support when claiming nor detailed information on what support or service was provided (Figure 112). In the 2022-23 financial year, 12.5 per cent of payments were self-managed.[1734]

Even when information is provided on what supports are provided, the accuracy of information provided can also be variable (Figure 112). For claims made through a Plan Manager, the accuracy of the information on the support and support provider depends on Plan Managers accurately inputting the support information, including the Australian Business Number (ABN) of the support provider. Participants also often have little visibility over claims made directly by the service provider to verify the claim's accuracy.

Figure 112: Data captured on NDIS markets depend on how supports are managed

Information on supports delivered	NDIA-managed NDIA IT systems administers payments to providers and provide visibility on spending and payments	Plan-managed Participant uses a registered plan management provider to monitor and manage spend	Self-managed Participant or their plan nominee monitor and manage spend themselves
What support was provided?	Support items in the NDIS support catalogue	Support items in the NDIS support catalogue	Support category
How much support was provided (including when)?	Itemised support quantity	Itemised support quantity	Total overall cost of supports being claimed – only detail required is first and last day of service; e.g. no details on quantity
How much the support costs the participant?	Itemised support prices	Itemised support prices	Total overall cost of supports being claimed only – no provision to provide itemised support prices
Who delivered the support?	ABN of support provider – verified as part of registration process, but no ongoing updates once registered	ABN of support provider – information quality depends on plan manager input	Limited – ABN or name of support provider is optional for self-managers to provide
Where support was delivered?	No information – assumes support is delivered in the area where a participant lives	No information – assumes support is delivered in the area where a participant lives	No information – assumes support is delivered in the area where a participant lives
How was the support delivered?	Limited information where pricing arrangements allow – such as specific items for delivering supports via telehealth	Limited information where pricing arrangements allow – such as specific items for delivering supports via telehealth	No information

Furthermore, feedback about service providers is typically collected across different government agencies, and often on the basis of a complaint being made or incident occurring. The various government agencies who collect feedback include: the NDIA, NDIS Commission, Australian Competition and Consumer Commission (ACCC), and state and territory governments. Each government body or agency can collect different pieces of feedback – for example, the NDIS Commission deals specifically with complaints relating to the compliance of NDIS providers with the NDIS Code of Conduct.

Therefore current systems and processes do not support the effective monitoring of NDIS markets. A lack of complete, accurate and timely information about who is delivering supports and services and what supports are being delivered provides a partial, inaccurate picture of the NDIS market. Coupled with fragmented feedback on service safety and quality, it is challenging for governments to understand what the market looks like and how the market is working.

Without complete and accurate information who is delivering supports and the quality of their services, governments are not able to effectively support participants to understand what good supports look like, nor to incentivise participants to choose safe and quality supports and services that suit their needs and preferences.

3.1.4 A centralised online platform is essential, underpinning infrastructure for strengthening the functioning of the NDIS market

For NDIS markets to function properly, it is clear that participants and providers need an online platform that centralises information. This should provide a complete picture of who is delivering supports and services in these markets. The online platform should be hosted (but not necessary operated) by the Australian Government and serve as the base for an appropriate information economy – where information is exchanged by 'buyers' and 'sellers' of goods and services in the market – to support participants and providers in making sound decisions.[1735]

Participants' desire for a way to easily search and engage providers and support workers can be seen in the uptake of current online platforms who match participants with support workers and providers. For many participants, these online platforms are "… a practical and accessible way for participants to explore who may be available (and suitable) to deliver the services they need".[1736]

However, current online platforms do not provide a complete registry of all providers or workers who deliver NDIS services. Instead, many online platforms rely on providers, workers and participants to sign up to their platforms. In addition, online platforms may have opaque contractual and fee arrangements with service providers (including independent contractors).

Participants and their decision-supporters need a complete and trusted online registry or database of all providers delivering supports - not just providers who have undergone the registration process or those who have signed up to a platform. Basic, essential information about each provider should be centralised for participants to easily search and compare. We call this a 'centralised online platform' (see Box 54).

Box 54: What the 'centralised online platform' should look like

The centralised online platform would be a complete, up-to-date database of all providers delivering NDIS supports and services with verified information on:

- what supports and services are offered by the provider, and where they deliver these services
- what prices providers are charging for supports and services

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- verified information on the quality and safety of each provider – this would include any compliance actions that have been taken against them. Once developed, provider performance measures should also be published as quality indicators (see Action 12.3).

The centralised online platform should also link in with the Disability Gateway for all people with disability to easily find information on available foundational supports. In the longer term, it should also provide functionality to search for local foundational supports.

Development of a centralised online registry of all providers should also simultaneously build on, and provide the enabling digital infrastructure for, the graduated, risk-proportionate provider regulatory approach (see Recommendation 17).

Under the new approach, all providers must be either enrolled or registered with the new National Disability Supports Quality and Safeguards Commission. Prospective providers could easily enrol or register through the centralised online platform (or via a link available on the centralised online platform), and the information provided through the enrolment or registration process would then be shared on the government online website (see Box 55).

Box 55: What the centralised online platform means for providers

As part of the new enrolment and registration process (see Recommendation 17), all providers of NDIS supports would have to provide basic information about their business, including:

- what supports or services they are delivering and where.
- the prices they are charging for supports. As part of Action 11.1, all providers would have strengthened requirements (with appropriate exemptions for smaller and enrolled only providers) to disclose relevant financial information and the prices they charge.

All providers would then be able to more easily:

- compare and benchmark their service offering and performance against others in the NDIS market.
- learn from verified feedback and ratings (see Action 12.3) about what is working well for participants and what participants value most for ongoing service improvement and innovation.
- develop an evidence base for what works and what doesn't work to inform their own support delivery approach and practices.

Figure 113: How providers could enrol or register through the centralised online platform

STEP 1: Provider completes an online application form via the centralised online platform (or a link available on the centralised online platform), providing:

- Legal / trading name
- ABN (or Digital ID where exempt from having an ABN)
- Bank account details
- Location (e.g. office address, outlet locations, service coverage)
- Contact details (e.g email address, phone number, mailing address)

The application process should leverage existing government systems and processes (e.g. MyGovID) to streamline requirements and strengthen identity verification.

STEP 2: As part of the online application form, provider nominates the types of supports they are intending to deliver for participants (e.g. from a checklist).

Provider is intending to deliver **high-, medium- and/or lower-risk supports.**

Provider is intending to deliver **lowest-risk supports.**

STEP 3: Provider attests to understanding obligations under the Code of Conduct and worker screening requirements.

Provider is directed to complete the registration process, with requirements proportionate to risks of their activities and operations based on the Provider Risk Framework.

STEP 4: Provider undergoes Advanced, General or Basic Registration with requirements proportionate to risk. This includes attestation and/or assessment of compliance with relevant Practice Standards, and a suitability assessment.

STEP 4: Provider is enrolled. Provider is directed to information and resources on being a provider, including insurance, tax and business resources.

STEP 5: Back-end data-sharing across NDIS systems

Relevant provider information is:

- Published on the online platform so that:
  — participants can search for providers based on support type, location, quality and safety metrics and other filters
  — providers can view their performance relative to the market
- Shared to NDIS payment system so participants can pay providers using fully electronic payments
- Used to inform coordinated scheme integrity measures

3.1.5 A place still exists for third party online platforms, but secure two-way information sharing would strengthen their role in supporting NDIS markets to function

The centralised online platform would offer people with disability, Navigators and the broader market more comprehensive and trusted information on available local services. But this would not replace the demand for third party online platforms in the scheme.[1737]

Box 56: What are third party online platforms?

A third party online platform is a digital service (or 'an online platform') which connects participants with service providers, including independent contractors.

Third party online platforms are one type of online platform in NDIS markets. Other online platforms include platforms that connect participants with support workers.

We refer to platform providers more generally as any providers who offer an online platform in NDIS markets.

People with disability will have varying levels of digital literacy, and will want to interact online, and with technology, in different ways.

- Some may want to only 'search' for local providers (such as, using the centralised online platform) while others might wish to 'search, book and pay' their providers all on the one platform.
- Some may also want to 'match' with providers through applying filters on what is important to them while others may want more personalised recommendations based on their specific needs and preferences.
- Some want to 'search' and/or 'search, book and pay' individual support workers rather than service providers.
- Some may need more time or help to use technology, and may wish to access information and get more help from their Navigator in finding and choosing services and providers who best meet their needs.

The vast range of accessibility, cultural considerations and other communication needs would also mean some participants want to interact online in different ways.[1738]

While governments can try to meet the needs and preferences of all people with disability, a single, centralised online platform will not be able to meet the diverse needs and preferences of all people with disability.

Instead, governments should encourage innovation and investment by third parties which build on the base government offering of the centralised online platform, alongside investing in Navigators (see Recommendation 4). Third party online platforms are likely to be more agile and responsive to

users and can provide a range of products that provide digital experiences tailored to different participants' needs and preferences.

The current range of third party online platforms supporting participants demonstrates the diversity of demand for new ways to find and interact with NDIS markets. However, there is a need for significant improvements in the operations of third party online platforms (see 0).

Box 57: Key opportunities for improvements in how platform providers operate[1739]

During 2023, the NDIS Commission undertook an *Own Motion Inquiry into Platform Providers* to examine how all platform providers, including third party online platforms, currently operate in the NDIS market.

The inquiry found platform providers can offer participants more choice and control over which service provider or support worker turns up and when. However, the inquiry identified some areas for improvement.

- How current platform providers ensure providers and workers (who sign up on their platforms) meet the appropriate quality and safeguarding arrangements is also inconsistent, with limited continuous monitoring. Some participants would welcome market-wide application of safeguarding structures.
- Platform providers' pricing structures can be opaque, variable and hard to compare. Some platforms charge fees for providers or workers to sign up on the platform or charge commissions for recommendations made to participants. Some platforms may 'skim' a proportion of the price charged by support workers or providers.
- More generally, it is difficult to compare platform providers. In addition to pricing structures, it is hard for participants to understand and compare the terms and conditions – such as around cancellations and insurance products and coverage – which differ across platforms.

One way to streamline how third-party online platforms operate in the scheme while fortifying incentives to innovate is through application programming interfaces (APIs).

Box 58: What is an application programming interface or API?

An application programming interface (API) is a tool that allows digital software and product developers to re-use or plug into parts of existing systems when designing and building new tools and products.[1740]

Government can provide access to APIs for software and product developers to build on government systems and tools. For example, the Australian Taxation Office (ATO) allows software developers to create bespoke accounting software and tools so that individuals and businesses can more easily manage their finances and associated taxes.

Government APIs would enable platform providers to build on the existing components of the online government services rather than starting from scratch. This would mean that platform providers can focus more of their efforts towards designing interactive user experiences tailored to the diverse needs of people with disability, and how people with disability wish to interact with the scheme and NDIS markets.

The NDIA do currently offer a number of APIs to registered service providers, Plan Managers and software developers – that is, businesses who develop and provide software to registered providers – through the NDIA Digital Partnership Office (DPO). However, the current range of APIs are heavily focussed on NDIS claiming processes, and less on enabling participants to connect with service providers.[1741] The NDIS Commission currently does not offer APIs.

APIs should be at the centre of the proposed new digital architecture to optimise innovation, efficiency and effectiveness. The NDIA and the new National Disability Supports Quality and Safeguards Commission will need to lead and coordinate this initiative. APIs offered by the NDIA and the new National Disability Supports Quality and Safeguards Commission will be slightly different. Where participants have given consent, NDIA could share information about participant budgets to allow participants to 'book or pay' providers through a third party online platform. The National Disability Supports Quality and Safeguards Commission could also use APIs to share information about which providers are registered and whether there have been compliance actions taken. Where possible, the processes and requirements for third party online platforms to access and use APIs should be aligned and streamlined to avoid unnecessary duplication and 'red tape'.

Extending APIs to third party online platforms could incentivise greater investment into delivering more significant value-add to people with disability when finding and connecting with service providers. Third party online platforms could build on the centralised online platform by offering people with disability other 'add-on' features and functionality tailored to their diverse needs. These could include ways to:

- Enable participants and their decision supports to use extra filters or fields based on provider search criteria that matter to them
- Get participants a 'better deal' by negotiating with providers on their platforms to offer supports at a higher quality and/or at better prices
- Give participants additional assistance in booking supports, or in understanding and monitoring their spending when engaging supports.

By allowing third party online platforms to plug into the centralised online platform, APIs could also increase the consistency in the information available on third party online platforms. This would ensure poor quality providers – who do not meet the appropriate quality and safeguarding standards and requirements – cannot get around these standards by using third party websites (see Box 59).

> **Box 59: How APIs could build on the centralised online platform**
>
> APIs developed by the NDIA and new National Disability Supports Quality and Safeguards Commission should be at the centre of the proposed new digital architecture supporting the effectiveness and efficiency of NDIS markets. The NDIA and new National Disability Supports Quality and Safeguards Commission could use APIs to share information with third-party online platforms to both streamline and strengthen the sign up process for users wishing to use their platforms. When signing up:
>
> - With appropriate permissions, APIs could enable new users to create an account with pre-filled information that they have already provided to the scheme. This would make it easier for people with disability and providers to use more than one platform.
> - APIs could enable third party online platform providers to have timely information about whether a new provider is allowed to deliver supports to people with disability. This would make sure banned providers are not allowed to sign up and use platforms in the first place – that is, providers cannot use third party online platforms to get around quality and safeguarding requirements.
> - APIs could also similarly enable third party online platforms access to information on what supports and services can be delivered by providers under the new regulatory approach.

While APIs could allow third party online platforms to plug into government systems, APIs could also allow governments to similarly plug into third party online platforms to strengthen market monitoring.

This two-way information sharing could help, in part, to address the current fragmented collection of participants' feedback on their experience with providers. APIs could be developed to coordinate collection of feedback from third party online platforms. This would:

- **Enable a 'no wrong door' approach for all people with disability to provide feedback and raise concerns**. This could mean that a person with disability would not have to interact with governments' bureaucratic processes and systems if they did not wish to, while also having confidence that their feedback and concerns would be securely shared with governments for appropriate response.
- **Strengthen governments' capacity and capability to monitor and steward the market**. More coordinated collection of qualitative market data would provide governments with more timely, complete information on individual incidents and emerging trends in the market. With this information, governments could better safeguard participants, and protect scheme integrity from non-compliance, sharp practice and fraud.

Extension of government APIs to third party online platforms would need to ensure the security of how the third-party online platforms store, use and share any information about their users. Third

party online platforms would need to meet the terms and conditions set out by the NDIA's Digital Partnership Office, and these should evolve over time with advancements in technology and cyber security threats.[1742]

To realise the improvements to the operations of third-party online platforms in the scheme, governments would also need to ensure that third party online platforms meet the following expectations:

- The minimum information available on a service provider provided by third party online platforms should not be less than the information about a service provider on the centralised online platform.
- All third-party online platforms should be transparent about their ownership structures, any actual or potential conflict of interests and any preferential listing or promotion of service providers.
- Third party online platforms who help connect participants with service providers should not charge participants sign-up or subscription-like fees to access or use their platform.
- Any fees charged by third party online platforms should be transparent and be clearly visible to participants in advance, every time they go to choose or purchase supports. This should include:
  - the total price of connecting and engaging with service providers (including independent contractors)
  - how much of the payment (in dollar and percentage terms) would go to the service providers (including independent contractors) and how much would go to the third-party online platform.
- The overall prices charged to participants by the third-party online platform and service providers (including independent contractors) should not exceed the relevant price caps (where price caps apply).

This information is essential for participants to understand and compare what is being offered by service providers (including independent contractors) on these platforms. For example, it would then be possible for participants to make informed choices on services providers with upfront, transparent information about the total price supports, including any fees charged, how much is paid to the platform and how much goes to the service provider. This would include whether the price of support is within the relevant price caps, where price caps apply.

It would then also be possible for participants and service providers (including independent contractors) to understand and compare what is being offered by third party online platforms. Free sign-up should encourage platform providers to streamline current processes to sign up and create online profiles (such as through using APIs) and make it easier for users to see how the platform works. Participants would also know if platforms have negotiated deals or discounts with specific service providers in return for promoting or preferentially listing.

These should be routinely reviewed and refined to ensure they remain fit-for-purpose as the market for third party online platforms in the scheme evolves.

Box 60: What could third party online platforms look like for participants

Participants should still be able to choose from a range of third party online platforms. Where third party online platforms sign up to use scheme APIs:

- It should be easier for participants to sign up to use third party online platforms. Participants can choose to streamline the sign-up process by consenting for information to be shared via APIs to 'pre-fill' their profile.
- Participants could have access to a range of bespoke features and functionality offered by third party online platforms. For example, some participants could use 'search, book and pay' all on the same platform. This could also include features like: the ability to schedule reminders for appointments, track spending against their NDIS budget, finding providers who understand their language or culture, more bespoke user-friendly interfaces from apps to websites, and so on.
- It should be easier for participants to find and compare the services offered and prices being charged by service providers (including independent contractors). This includes any actual or potential conflict of interests, any preferential listing or promotion of service providers, how much would be paid to the platform, and how much would be paid to service provider. Information about the safety and quality of supports delivered by the service provider would also be easily accessible and provided more consistently so it is easier to understand.
- Participants can also provide feedback about their service providers through the third party online platform. APIs could be designed for this feedback to be shared directly to the NDIA or the new National Disability Supports Quality and Safeguards Commission so that participants, their families or carers would not need to separately raise any concerns or complaints with governments.
- Participants should have greater confidence in how their information is being collected, used, stored and handled where third party online platforms are using APIs. Third party online platforms will have to comply with relevant Australian Governments terms and conditions in accessing APIs. This includes information security and handling.
- Participants can still choose to use third party online platforms who do not use scheme APIs, but may miss out on some of the benefits around easier sign-up processes. All third party platforms should still have to: provide minimum information about service providers (including independent contractors), not charge participants sign-up or subscription-like fees to access or use their platform, be transparent about their ownership, pricing and fee structures, and comply with relevant pricing regulation (where applicable).

Box 61: What could third party online platforms look like for providers

Providers (including independent contractors) should still be able sign up and list their supports and service on a range of third party online platforms. There would be a range of benefits:

- Providers (including independent contractors) should be able to more easily access and compare information on who else is delivering services and supports in NDIS markets.
- Providers (including independent contractors) should also have more transparency over the different pricing and fee structures of different platforms. This includes how much would be charged for connections made through the platform, and how much would be paid to service providers (including independent contractors) for supports delivered.
- Signing up should be more streamlined, and quality and safeguarding requirements should apply consistently across the different platforms.
- Providers (including independent contractors) should not be able to use third party online platforms to get around relevant quality and safeguarding arrangements, or price caps (where they apply).

3.1.6   Action & Implementation Details

Action 10.1: The <u>Australian Government</u> should develop and fund an easy-to-use centralised online platform that provides information on all locally available supports and services for participants and Navigators.

An online registry should provide participants and Navigators with essential, accessible, timely and reliable information to search for providers by location and service type. This should cover all available, local NDIS providers, including registered and enrolled providers (see Action 17.1). Information on how much supports cost and provider performance (see Action 12.3) should be centralised to make it easier for participants and Navigators to compare providers based on price, safety and quality of their service. The centralised online platform should also include information about available foundational supports (see Actions 1.3 and 1.4).

Implementation detail:

- The NDIA should work with people with disability, service providers, support workers and other Australian Government agencies to scope design features and functionality for an accessible centralised online platform for searching providers. This should consider opportunities to leverage existing government ICT infrastructure.
- As a first step, the NDIA and new National Disability Supports Quality and Safeguards Commission should consolidate and centralise information on currently registered NDIS

providers across the NDIA and National Disability Supports Quality and Safeguards Commission websites. Over time, the centralised online platform would replace the existing NDIS Provider Finder tool.

- The NDIA and new National Disability Supports Quality and Safeguards Commission should gather information on all providers as part of the risk-proportionate model of provider regulation (see Action 17.1), and transition to list all providers on the centralised online platform. Where possible, this should leverage existing digital identity verification systems (such as myGovID) to strengthen scheme integrity and minimise burden for providers, particularly for those delivering supports across the care and support sector.

- The NDIA should work with the new National Disability Supports Quality and Safeguards Commission and Australian Government and state and territory government agencies to design and implement a strategy to collect and share information on provider performance (see Action 12.3), including a provider performance framework, and information-sharing arrangements to source participant feedback collected via third party online platforms (see Action 10.2).

Action 10.2: The National Disability Insurance Agency and the new National Disability Supports Quality and Safeguards Commission should enable better two-way information sharing with third party online platforms to encourage digital innovation that builds on the centralised online platform.

The National Disability Insurance Agency's current application programming interface (API) functionality should be expanded to enable better two-way information sharing. This should build on what is offered by the centralised online platform (see Action 10.1) and provide participants with a more tailored digital experience. Information sharing arrangements should comply with relevant privacy, information handling and data security requirements.

Information sharing arrangements could also be designed to enable third party online platforms who help connect participants with service providers to share information collected on participants' experiences with providers, and governments to share consistent, reliable provider information across platforms. This would improve governments' market monitoring capability and enable more timely response to quality and safety concerns.

Implementation detail:

- The NDIA and new National Disability Supports Quality and Safeguards Commission should work with third party online platforms to design and build APIs to enable secure two-way information sharing between the scheme and platform providers. APIs should be at the centre of the proposed new digital architecture to provide for maximum efficiency and effectiveness. APIs should be:

- designed to facilitate more coordinated data collection of participants' experiences with providers for improved monitoring and responses to safeguarding concerns

- only enable sharing of participant information on a "need to know" basis or where consent has been provided, and support third party online platforms to innovate in delivering a more tailored, harmonious digital experience for people with disability.

- The NDIA and new National Disability Supports Quality and Safeguards Commission should also ensure appropriate arrangements are in place for third party online platforms and these arrangements should be routinely reviewed and updated to ensure they remain fit-for-purpose as the market evolves. These arrangements should also be aligned to the broader regulatory approach under Recommendation 17 to ensure:

  - *transparency of information on providers* - third-party online platforms that help connect participants and service providers should not provide less information than the centralised online platform (see Action 10.1). Third-party online platforms should also be transparent about their ownership structures, any actual or potential conflicts of interest and any preferential listing or promotion of service providers.

  - *transparency in pricing structures* - third party online platforms who help connect participants with service providers should not charge participants sign-up or subscription-like fees to access or use their platform. Any fees charged by third party online platforms should be transparent and be clearly visible to participants in advance, every time they go to choose or purchase supports. This should include: the total price of connecting and engaging with service providers (including independent contractors), and how much of the payment (in dollar and percentage terms) would go to the service providers (including independent contractors) and how much would go to the third party online platform.

  - *compliance with price regulation* - third party online platforms should not charge participants fees for using their platform. However, third party online platforms may charge service providers (including independent contractors) fees for using their platform. The overall prices charged to participants by the online platform and service provider (including independent contractors) should not exceed the relevant price caps (where price caps apply).

3.2. Investment in the NDIS digital infrastructure provides critical and timely information for participants to manage funding, and for governments to monitor markets

To make informed decisions, participants, their families and carers also need more accessible, timely and reliable information about what supports they are funded for, how much they have allocated and used, and how much they have left.

While the NDIA has made efforts to improve its processes and systems, managing and monitoring spending is still challenging and administratively burdensome for many participants. There is also significant confusion about who should be doing what in helping participants to understand, use and manage their budgets.

Alongside a new approach to delivering navigation supports, investing in the NDIS digital infrastructure is needed to capture more complete and timely information on transactions in the scheme, and to make it easier and faster for participants to pay for supports. This would support participants and their Navigators to make more informed decisions about spending, including choosing and engaging with service providers. Governments would also have more comprehensive and timely information to undertake more evidence-based market monitoring (see Recommendation 13), support more effective stewardship of the market (including setting price caps) and better protect the integrity of the scheme.

3.2.1 Self-management has been a game-changer for many participants, but managing budgets needs to be made easier

Self-management has offered many participants with much greater freedom to choose and control what supports and services they want to purchase using their funds, how supports and services are delivered and by who, and how much they pay for these services.[1743]

> *"My plan is self managed. The freedom of choice and control has been a game changer for me. It is imperative that we continue to have choice and control over our daily life including choosing who supports us." – Participant[1744]*

Yet, self-managing budgets can be unnecessarily difficult for many participants.

There is a complex and ever-changing maze of rules for participants to navigate to understand how budgets can and cannot be used. While the NDIA has updated guidance and resources for self-managers,[1745] many self-managing participants and their nominees have told the Review they need consistent, accessible information and messaging on what is allowed as well as clearer guidance on self-managers' rights and responsibilities.[1746]

> *"Self managed can be complex as there is no simple guide to assist with the types of uses for funding - I'm always worried the things my son needs may not be 'permitted'." – Carer[1747]*
>
> *"Overwhelming amount of information on website. Not easy to try to understand if you are able to purchase something ... there often seems to be conflicting information and I don't want to live in fear of being audited and having to repay or have self-managed revoked which is what some people are claiming." – Carer[1748]*
>
> *"I find the isolation of being a self-managed NDIS participant breathtakingly cruel. There is no one to talk to on matters to do with the NDIS because no one is funded to deal with me. And please do not talk to me about the help line, the LAC, the provider*

of services or even the participant newsletter. There are no meetings of the self-managed, no forums, nothing. I am never even part of the target demographic. I have never seen anything that talks about the self-managed. I am invisible and isolated." – Participant[1749]

NDIS policies provide unclear guidance, creating confusion and anxiety for participants. NDIS processes and systems are similarly hard to navigate and use (see Chapter 2).

Paying for supports can take a lot of work, and can be slow

To make a claim and pay for supports, currently participants, their Plan Manager or their service provider have to key in the details of the invoice or receipt into the NDIS portal, or in a spreadsheet for bulk claims that can be uploaded into the portal. This is a typically highly manual process, although some service providers and Plan Managers have invested in their own technology that can automate all or part of this process.

The highly manual claiming processes create significant opportunity for human error to occur. This can lead to additional time for providers, Plan Managers and some participants to reconcile any claiming errors to ensure a claim is valid.

The NDIA report 98 per cent of valid claims are paid within 24 to 48 hours.[1750] However, this is only based on the time it takes for the NDIS payment system to pay self-managing participants, Plan Managers or agency-managed service providers. In a small number of cases, we have heard it can even take over a year for some service providers to be paid after a service has been delivered.

We have heard there can be considerable delays for providers to be paid for services delivered, particularly when using a Plan Manager. For participants using a Plan Manager, payments may be delayed by additional payment assurance checks which are conducted by some (but not all) Plan Managers. Plan Managers are expected to validate invoices within no more than five business days, and pay the service provider (or participant where it is a reimbursement) within two business days.[1751]

> *"Payments under Medicare have also been significantly automated to enable people using the service to pay on the day, and there are other in-built system features that streamline the rebate process. Conversely, under the NDIS, speech pathologists predominantly experience delays in receiving payments, particularly from plan managers, and report a significant time-cost in chasing these payments." – Speech Pathology Australia[1752]*

Delays in paying valid claims may also arise from disputes between service providers and participants who are self-managing or using a Plan Manager.

> *"There is currently no recourse or avenue to providers such as [Provider] to request NDIS investigate invoice disputes. At present, the provider must bear financial burden with the only course of action open to providers to take each objection, based on each individual invoice to the Small Claims Tribunal. The current waiting time per claim is*

in excess of six months yet some participants are refusing invoices for services provided, on a weekly basis. These challenges result in considerable pressure on cashflow. Even as a large organisation, this cashflow pressure is difficult to sustain and must be an existential threat to smaller service providers." – Provider[1753]

It is also difficult to keep track of how much funding is left in a participant's budget

Tracking spend and managing a budget is often tricky, and can require a lot of time, effort or help. Delays in claims being paid after services are delivered also means that information on how much budget has been spent is also delayed. It is difficult for participants to track spending and manage their budget without timely payment information.

While self-managed participants have the most choice and control over their budget and supports, they also have the most responsibility in tracking how much of their budget they have spent, including what they have allocated to services but not yet used. Often this can take a lot of time, effort and work.

"There is lack of clarity on the processes we are meant to follow and nowhere to access that information in a simple, easy to understand manner. I'm self managed and the claiming of funds is ridiculous. The categories of funding on the plan do not match up with the categories we are provided with to claim funds." – Participant[1754]

This could partly explain why the rate of participants choosing to self-manage all or part of their budget has stayed steady at around 30 per cent (Figure 114), with around 80 per cent of self-managers being child representatives or plan nominees managing on behalf of the participant (Figure 115).

Figure 114: Number of active self-managing participants by age group, and who is self-managing funding as at 30 June 2023[1755]
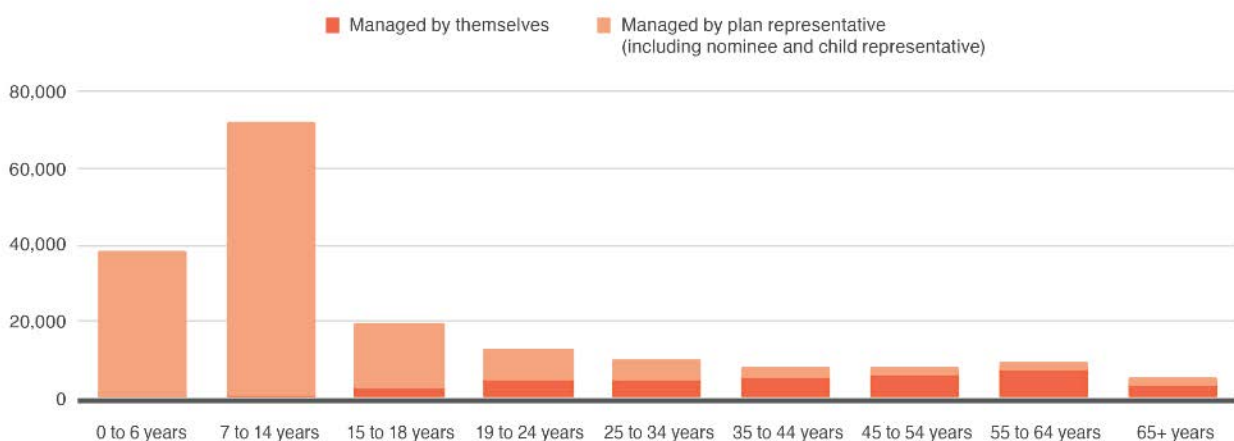
3.2.2 Help for participants to track spend and manage their budgets is highly variable in quality due to continued lack of clarity in expectations and responsibilities

Difficult-to-navigate digital infrastructure and the complex web of information and guidance is in part driving the rapid growth in participants using Plan Managers to help process their invoices, pay providers and manage their budgets. Access to unregistered providers is also likely driving participant choice in using a Plan Manager, with a steady proportion of participants shifting from agency-management to using a Plan Manager.

> *"Being plan managed means [I] can choose my providers without the hassle of self management." – Participant[1756]*

During 2022-23, more than 50 per cent of all NDIS transactions were processed through Plan Managers, totalling over $17 billion of all payments.[1757]

Figure 115: Distribution of active participants by method of financial plan management over 2020-23[1758]
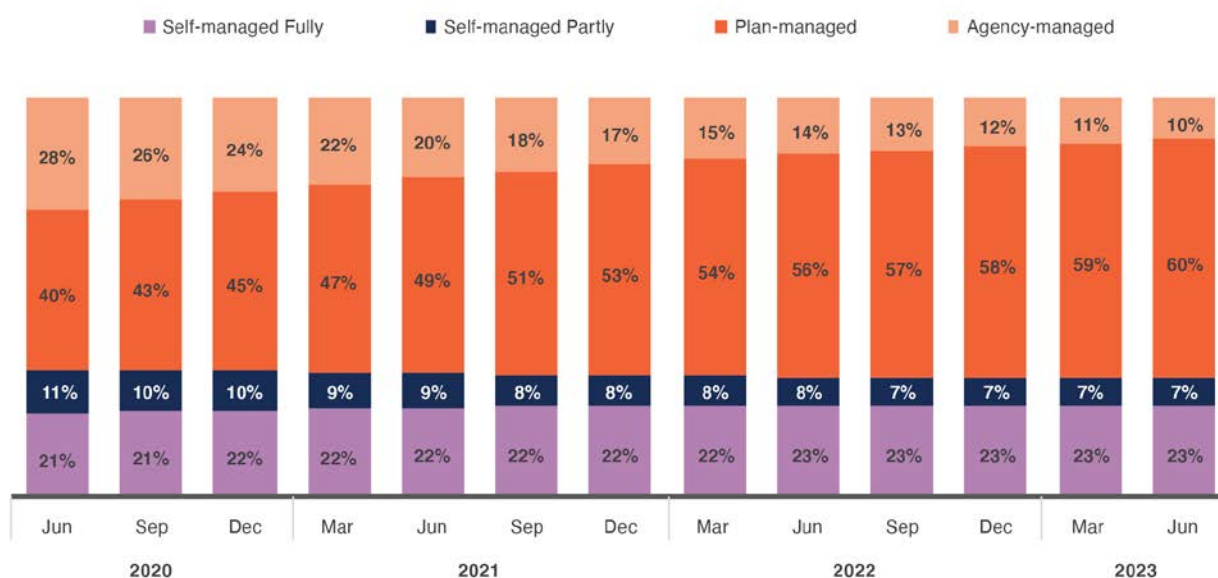
Despite widespread uptake in plan management, help for participants to understand, use and manage their budget can vary significantly

The plan management market was valued at $485 million in 2022-23, as measured by total plan management fees.[1759] In 2022-23, there were over 1,400 providers delivering plan management services, with the top 10 largest Plan Managers receiving almost 40 per cent of all plan management fees paid.[1760]

Figure 116: Distribution of market share by size of plan managers, based on plan management fees paid in 2022-23 [1761]
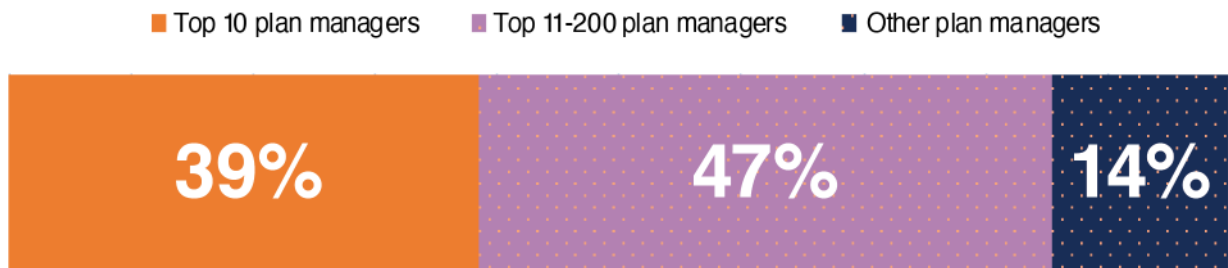
The quality of plan management services varies considerably across all Plan Managers due to a lack of clarity and consistency in expectations[1762]

Participants and other Plan Managers have suggested that some plan management providers act as 'transaction clearinghouses'. We have heard that some Plan Managers provide very few checks over invoices they process, and little help for participants to monitor spending or to financially manage their budget.

> *"I also think the plan management option is a waste of money for very little benefit. My experience with a plan manager was stressful and created so much extra admin work for me as I was constantly chasing them to pay invoices so AT or consumable goods could be released by suppliers. They also never checked invoices or picked up mistakes when providers have charged incorrectly." - Carer[1763]*

In part, this could explain recent analysis which indicates that, of the three financial plan management methods, plans that are managed by a Plan Manager have experienced relatively higher inflation in between plan reassessments for the 12 month period up to 31 March 2023.[1764] However, this inflation may have also resulted from legitimate changes in circumstances or a reduction in a previous plan budget.

On the other hand, we have heard that some Plan Managers do provide more help in tracking spending – such as through budgeting tools or software – or dedicated resources to help participants understand how their budget can be used and to financially manage their budget.[1765]

> *"I'm constantly checking billing amounts of my own events or services obtained against invoices against my NDIS fund amount. I also have to approve each invoice to which I've created my own spreadsheet to ensure correct amounts and procedure is maintained with cross checking. If I see any variations or errors I engage them directly. Note: I have a plan manager which they've given me a phone app where I approve invoices and I see overall expenditures and remaining fund amount that I check against my own records." – Participant[1766]*

Although Plan Managers can undoubtedly do more to help participants financially manage their budget, current systems and processes can hinder the ability of Plan Managers to effectively support participants to make informed budgeting and spending decisions.[1767]

- Plan Managers often only have visibility over where, and how much, budget a participant has at the point when an invoice has been received. It can often be too late to provide advice or take action where participant has already over-committed their budget.
- Equally, where a participant has a Support Coordinator, the Support Coordinator may not have consent to view a participant's plan. This can lead to Support Coordinators inadvertently providing incorrect advice to a participant, which leads to participants overcommitting their budget. Plan Managers may not be privy to this advice either, which can further hinder Plan Managers in supporting participants to manage their budget (see below).
- Even when Plan Managers or Support Coordinators provide advance warnings or advice to participants about potentially using up their budget faster than expected, it is ultimately the participant's decision as to how they spend their budget.[1768] This can be critical to a participant's journey in learning how to manage their budget for themselves. At the same time, there can be little incentive for Support Coordinator or service providers to ensure that funding lasts the duration of the budget.[1769]

The roles and responsibilities of other intermediaries add further confusion in what Plan Managers should be doing to help participants in understanding, using and managing their budget[1770]

> *"Intermediary roles are arguably both a product of there being too much complexity in the Scheme and a source of additional complexity within the Scheme. … Additionally, the intermediary roles of support coordination and plan management emerged without a clear alignment to the participant pathway, distinct boundaries between roles, or coherence with Scheme values. These roles remain ill-defined and many participants are confused about who can assist them with which elements of the Scheme." – JFA Purple Orange[1771]*

As at 30 June 2023, over 65 per cent of all participants have access to two or more intermediaries to help them navigate the scheme. Of these participants, 57 per cent had funding for support coordination and plan management in their budget.[1772]

We have heard of instances when having a Support Coordinator and Plan Manager can work well.

> *"I like the plan management system whereby all invoices are sent to the plan manager. I also like having a support coordinator who can monitor and deal with situations that I can't deal with" – Participant[1773]*

However, we have also heard that managing how a budget is used and paying providers is a confusing and stressful experience for participants with both a Plan Manager and a Support Coordinator, and some see little value in having a Support Coordinator and Plan Manager.

"I've been allocated seven support coordinators. There was a period of five months when almost all my limited energy went into trying to replace support coordinators who had left instead of getting actual supports in place. Most of my funds have not been spent, and much of what has been spent has gone to support coordination and plan management with little to show for it." – Participant[1774]

The participant's Local Area Coordinator or the Support Coordinator (where funded) is responsible for helping a participant to understand their support budgets and what they can be used for, not the Plan Manager. Where a participant needs more help, a Support Coordinator is typically funded to assist participants with arranging and coordinating their supports.[1775]

Even among NDIA planners, Local Area Coordinators and Support Coordinators, there is often a lack of shared understanding about what is funded and, as a result, what can be purchased using an NDIS budget (see Chapter 2). The role of the Plan Manager in implementing the budget plan is also unclear, since Plan Managers are meant to be responsible for 'spending in accordance with the plan'.[1776]

The Plan Manager is often not involved in discussions with the participant, their NDIA planner, Local Area Coordinator or Support Coordinator (where funded) about how the participant's budget can be used. Often the participant's Plan Manager can only rely on the information about the NDIS plan which the participant has consented to share with the Plan Manager, and complex website guidance in figuring out whether their NDIS budget can be used to pay for the support or service.[1777]

"When there is not enough education or support for people who do not have the benefit of having a support coordinator - organizations, plan managers and support workers end up doing the job for them - this is unpaid work and it is also dangerous as they may not have the correct information and often think they are helping people by saying something like 'you can get XYZ because I know someone who got it paid for by their plan'." – Provider[1778]

We have heard that where the participant's Plan Manager has a different understanding of how a budget can be used to that of the participant's Support Coordinator or service provider, disputes arise about whether the Plan Manager should pay for supports already delivered using a participant's NDIS budget.[1779] What communication or assistance is provided by the Plan Manager to participants and service providers in resolving these disputes can vary greatly, with some Plan Managers reported to provide no communication or assistance at all.[1780]

Disputes around whether invoices should be paid can also arise between participants and Plan Managers. We have heard that in some instances, participants 'shop around' for Plan Managers who are less likely to decline or reject invoices.[1781]

We have also heard that the current NDIS payment system has seen the NDIA attempting to recover non-compliant payments from service providers through the Plan Manager. Plan Managers have raised concerns about the liability risk that this presents to them, and have argued that this

has created a shift towards a greater focus on payment compliance at the cost of providing value-based supports.[1782]

Yet, despite the confusion in roles and responsibilities, having a Plan Manager can often be better than having little to no assistance at all in monitoring support budgets. In spite of being called "agency-management", the NDIA provides little help or support to monitor and manage budgets. Unless they regularly log into the NDIS portal, participants, their families and carers have little to no visibility over how much of their budget has already been allocated or spent. Even then, it can be difficult to understand how much of their budget they have remaining.

> *"The portal that enables participants with agency-managed supports to access information and monitor spending is not user friendly, including in basic aspects such as the names of support categories, with many given different names to what appears in a plan." – JFA Purple Orange[1783]*

3.2.3 Investing in NDIS digital infrastructure would enable better participant outcomes and improve market monitoring

To address the confusion and challenges in managing budgets and payments, participants, their decision-supporters (including nominees) and Navigators need more timely information to make informed decisions. Governments also need more complete, timely information to effectively monitor and steward markets. Improvements to the enabling NDIS digital infrastructure are key.

Investment in the NDIS digital infrastructure should focus on:

- transitioning towards fully electronic payments that makes it easier and faster to pay for supports and services delivered
- a parallel uplift in NDIS system controls to protect scheme integrity.

Alongside changes to supporting people with disability to navigate the scheme (see Recommendation 4), there should be a transition in how participants can manage their budgets, and who would support them to do this.

Investments in the NDIS digital architecture should be coordinated and sequenced to enable the broader reforms we have recommended, and align with the broader whole-of-government agenda and approach to digital transformation.

Together these actions are needed to help participants better manage their NDIS budgets. These actions will also help governments to better monitor and respond to issues in markets, and protect the integrity of the scheme.

3.2.4 Transitioning to fully electronic NDIS payments would make it easier for participants to pay their providers, manage their budget and improve governments' capability to monitor the NDIS market

Evolution of payments technology in recent decades presents governments with the opportunity to make paying for funded supports easier and faster.[1784] These payment technologies also provide

governments with improved visibility of transactions to more effectively steward the market and to better protect the integrity of the scheme.

The last few decades have seen a move away from cash-based payments. With the NDIA's current back-end payments engine fast becoming out-dated, the NDIS has a valuable opportunity to invest in a more fit-for-purpose and agile payments engine that supports a streamlined, multi-channel digital payments approach.

Improving current NDIS payment and claiming channels and introducing additional, streamlined electronic payment methods would be key to providing participants, providers and governments with the information they need to make decisions and take action in NDIS markets.

A multi-channel digital payment system would be able to provide more up-to-date information for participants, their families, carers and Navigators to better track and manage their NDIS spending (see Box 62). Having more options around how to pay electronically also offers participants with more say over how much visibility and control they want to have over their spending, including how much help they want from their Navigator with regard to tracking spending.

Box 62: What the future NDIS electronic payment system means for participants

Under the future multi-channel digital payment approach, all participants and their plan decision-making supports should be able to pay for their supports easier, faster and using more ways than they do today. The future multi-channel digital payment approach should be designed so that:

- participants and their decision supporters (including nominees) would be able to pay all providers through the system since all providers of NDIS supports would either be enrolled or registered under the new risk-proportionate regulatory model (see Recommendation 17).
- help from a Plan Manager to manage their budget may no longer be needed by the participant and their decision supporters (if they wish to fully self-manage) or could gradually shift to the participant's Navigator. Where needed, the participant's Navigator would support the participant and their decision-supporters to monitor and manage spending (see Recommendation 4).
- participants and their decision-supporters (including nominees) would no longer need to pay for supports and services using their own money and then seek a reimbursement from the NDIS. This means that participants and their decision-supporters (including nominees) – mainly those who are self-managing – will no longer have to wear the personal financial risk should a claim for reimbursement be declined.
- evidence and documentation would need to be provided to support all claims (including for fully self-managing participants) but would be less administratively burdensome for participants and their decision-supporters (including nominees). For instance, participants and their decision-supporters (including nominees) might not need to supply evidence

> themselves as they could receive and pay electronic invoices through the NDIS payment system. In other cases, participants and their decision-supporters (including nominees) could also just 'tap and go'.
> - all participants, their decision-supporters and their Navigator would have access to near-real time information and updates on how much budget they have, how much has been allocated and used. This would help participants and their decision-supporters (including nominees) to make more informed purchasing decisions and to more effectively manage their budgets, including accessing support from their Navigator where needed.

To make it easier to manage budgets, a multi-channel digital payments system should be integrated with other NDIS digital tools in monitoring spend and managing budgets - such as, the myNDIS mobile application (or 'mobile app') and the current participant portals.

> *"The app is great and makes self management easy. It's still a bit of a burden and having a recurring claim might be easier (but has the potential for things to go wrong if not cancelled)." – Participant[1785]*

> *"...I like using the [participant] portal on [MyGov], it works much better these days, I can cancel payment requests if I make a mistake and I can add information in descriptions so I always know what each claim was for. It would be even better if I could sort requests by provider or funding category etc ...I am not interested in using an app." – Participant[1786]*

As paying for supports and services becomes easier and faster, all NDIS transactions should become fully electronic and occur through the NDIS system. Participants should be able to continue to pay upfront and seek reimbursements in the short term, but this method of payment should be phased out over time.

This would mean that, under the future digital NDIS system, Plan Managers would no longer 'pay the bills'. Service providers would be paid through more automated processes which involve less manual data entry and administrative effort to resolve claiming errors.

In doing so, governments would be able to capture more information on all supports being purchased. This would include who is delivering the supports, how supports are being delivered, the actual prices paid for supports, and the locations where supports are delivered. This would increase governments' visibility of what is happening in NDIS markets. With increased market visibility, governments would have more capacity and capability to proactively monitor NDIS markets for emerging market opportunities and gaps, as well as risks to the scheme integrity. Over time, more information on 'inputs' and participant outcomes would emerge.

How a multi-channel digital NDIS payment system could work

One way the NDIA could implement a fully electronic NDIS payments is by digitising the invoicing process. Rather than generating invoices on their own systems and sending to the participants or their plan manager, some providers could generate and send invoices to participants and their decision-supporters (including nominees) through the NDIS payment system. This would make it easier and faster for participants and their decision-supporters (including nominees) to check and validate the invoice. Claims could also occur faster as information on electronic invoices could automatically be pre-filled.

Another way to streamline claiming processes would be to leverage existing point of sale technology, which would enable participants and their decision-supporters (including nominees) to 'tap and go' after a support is delivered. Point of sale solutions - such as by pre-configuring settings in any point of sale terminals - could be designed to systematically collect critical information about the transaction and automatically generate associated electronic receipts. However, the speed and simplicity of tap and go would need to be balanced against potential risks of exploitation.

The NDIA has commenced preliminary work to explore the use of point of sale technology – or claims at point of support (C-POS) – for claims and payments to be made in near real-time.[1787] Although in its infancy, C-POS could make paying for supports easier and faster, while also making it less burdensome for participants and providers to give information and evidence on what supports were delivered, who delivered these supports, and where the supports were delivered. Other important benefits could also include not having to disclose personal details and plan information for low-value, one-off purchases.

Testing near real-time claims technology should start with identifying areas where there is the least friction and the greatest benefit. Most allied health services already have access to point of sale claims and payments technology through the Health Industry Claims and Payment Service (HICAPS), and there is already work underway to integrate this within NDIS payment systems.[1788]

But C-POS would not replace the broader multi-channel digital payment system. Instead, C-POS could add to the payment channels available, and be part of the broader multi-channel digital payment system. This is because not all supports are delivered in a way which paying via point of sale technology would make sense – for instance, some larger-value assistive technology or more complex home modifications are often delivered in stages or iterations. Further, not all participants will want to pay immediately after supports and services are delivered – for example, participants or their nominees may want time to understand and check invoices before paying, as part of managing their budget.

Figure 117: Illustration of how a multi-channel digital NDIS payment system could work

STEP 1: Initiate a claim to pay for support or service delivered
Participant (with help from their Navigator) or provider creates and submits a claim using one of the following methods.

Using point of sale technology:
i. Provider keys in claim details in point of sale terminal or platform
ii. Participant can "tap and go" with an NDIS 'card' or digital wallet*.

*Note: This is only an illustration of what the design of this technology could look like.

Using invoice:
i. Provider sends invoice to participant (and their Navigator)
ii. Participant checks invoice.
iii. After verifying the invoice, participant either: approves invoice through system (if invoice sent via NDIS payment system), or uploads and submits invoice (if invoice is sent outside NDIS payment system).

Reimbursement:†
i. Participant pays for support upfront using own money.
ii. Participant creates a claim for reimbursement and uploads receipt into NDIS system.

STEP 2: NDIS payment system conducts checks and validations NDIS payment system performs a range of rule-based checks and validations on the claim. These include (but are not limited to):

Is there enough funding remaining in the participant's budget to pay the claim?

Is the support item being claimed in line with price limits and claiming rules (where applicable)?

Is the provider allowed to deliver the support?

For high-, medium-, lower-risk supports:
Is the provider appropriately registered (Advanced, General or Basic Registration)?

For lowest-risk supports:
Is the provider enrolled?

All payment validations and checks are successfully passed:
- Provider is paid for supports by the system; or
- Participant is reimbursed.†

At least one payment validation or check is not successfully passed:
- Provider is not paid OR participant is not reimbursed the full amount.
- Provider / participant needs to either: reconcile any errors or raise payment enquiry to resolve.

STEP 3: PAYMENT OUTCOMES

†Note: Reimbursements as a mode of payment should phase out as NDIS transitions to fully electronic payments

3.2.5 Parallel improvements to the NDIS digital infrastructure are a priority to strengthen scheme integrity

Increased visibility of all transactions alone will not be sufficient to strengthen scheme integrity without more effective fraud risk controls and responses.

> *Providers can claim payment from NDIA or Plan Managers without confirmation from participants that the services were provided. Similarly, self-managed participants can submit claims for payment without providing evidence of services provided (although they are expected to retain evidence). These payment arrangements pose a high risk of fraud. – ANAO Report on 'Effectiveness of the National Disability Insurance Agency's Management of Assistance with Daily Life Supports', 2023[1789]*

We have heard from participants, their family and carers, service providers, intermediaries and others about the many risks to the integrity of the scheme.

> *"When you are ripped off by a dodgy provider it is up to you to get the money back and the NDIS don't help and don't even offer additional funds to help in the mean time. This happened to me and I was SHOCKED" – Participant[1790]*

> *"In my own experience, a well-known gardening service over charged me nearly three times per hour the rate set out in the NDIS costings for yard maintenance. I was also sent multiple invoices in hope to receive duplicated payments from me. I challenged this and the duplicated invoices ceased.... It seems that when funding is government sourced, there is an attitude of take, take. It was also apparent to me that the gardener considered me an easy target as a person lesser than normal." – Participant[1791]*

> *"You see a lot of dialogue from self-managed participants saying - 'go self-managed' because you can then purchase it yourself and claim it - a plan-manager can't tell you you can't have it etc. the fact is that EVERYONE is bound by the same rules - the only exception is that self-managed are not bound by the price-cap in the price guide - that is not understood or clear" – Provider[1792]*

> *"NDIS plans should be clearer on how the funding can be spent. Yes there is choice and control and this is important to participants but there are concerns as a service provider that when you explain to a participant on how their funding can be spent, these suggestions are ignored, resulting in participants abusing the NDIS scheme and budgets being over spent." – Provider[1793]*

The ANAO found that the inadequate payment system controls have made it easy for people to exploit the scheme. This includes intentionally claiming for goods and services that aren't included in the NDIS plan, charging for goods and services that were not delivered, and charging more than once for goods and services delivered.[1794]

Similarly we have heard from participants and providers that the lack of the necessary payment system validations and other controls is making it easy to do the wrong thing unintentionally. For example, the current payment system can send the wrong signals that the claim is valid when it isn't. Often this can mean participants and providers face the stress of having to pay back the money long after it is claimed because the NDIA can take a long time to discover that the payment should not have been made.

> *"NDIS has a very broken payment system. It allows anyone to claim anything they want. The system doesn't allow user to pay back money which means if a mistake is made the government never get the money back. Due to the poor system, we have to [spend] extra money to stop the fraud which doesn't make sense to me. I would suggest the government to invest resources at the beginning to make the payment system more secure to stop people from claiming dodgy invoices." – Anonymous[1795]*

The NDIA has advised that the scheme has "… greater integrity vulnerabilities than other Commonwealth payment programs". However, the NDIA is unable to provide "… a precise estimate of financial loss due to fraud and non-compliance in the NDIS … because of incomplete data".

In addition to the Australian Government's investment into "cracking down" on current non-compliance and fraud,[1796] much more needs to be done to invest in the digital infrastructure to design and operationalise payment and other scheme integrity measures.

Ensuring the scheme's digital infrastructure is fit-for-purpose and has sufficient agility to respond to emerging scheme integrity risks would be a critical part of a holistic approach in protecting the integrity of the scheme

Advancements in technology have seen the emergence of increasingly sophisticated ways to take advantage of individuals, organisations and governments. How governments use technology needs to be more agile and responsive to keep pace with these threats to the integrity of the scheme.[1797]

Investment in the enabling digital infrastructure of the NDIS is needed to address current key system vulnerabilities and to progress the scheme reforms proposed by the Review. Moving towards a more consistent and robust approach to determining eligibility to access the NDIS (see Action 3.1) and a risk-proportionate model of regulation (see Recommendation 17) provides opportunity to refine and strengthen the controls for those looking to access and engage with the scheme (see Box 63).

> **Box 63: More robust identity verification through the Australian Government's Digital Identity program could help to stop sharp practice and fraud at the start**
>
> In response to increasing cyber security threats, the Australian Government's *Digital Identity Program* provides an easy, secure and convenient way to ensure individuals and organisations are who they say they are. For governments, a Digital Identity makes it easier to verify people and businesses are who they say they are, and would better prevent unscrupulous individuals and organisations from gaining access to the scheme in the first place.

There are opportunities to adopt existing government Digital Identities (such as MyGovID), which can already link into NDIS infrastructure.

Some Digital Identities (such as MyGovID) are also used across different government services. Using existing government services would, therefore, make it easier for people with disability and providers to access the supports they need across government.

The Productivity Commission's latest five year Productivity Inquiry Report recommended that Australian Governments should increase access to the Australian Government Digital Identity and "work towards adopting a single national digital identity, rather than different jurisdictions having fragmented identity systems that require citizens to verify their identity with governments and businesses through different channels." [1798]

Digital Identities that are used across government would also make it more efficient to share critical data to prevent sharp practice, fraud and criminal activity (where appropriate). This would also make it easier for governments to prevent those who have a past history of committing fraud in other government schemes and programs from being allowed to engage with the NDIS and participants.

Clearer policy, guidance and education resources would also be essential for Navigators to support the trust-based approach

More flexible budgets (see Action 3.5) and a trust-based approach to monitoring spend (see Action 3.6) requires clearer and easier-to-understand policy, guidance and education resources. Without these, it will continue to be difficult for participants, their decision-supporters (including nominees), providers and workers alike to know what is the right thing to do. Indeed, we have heard that 'doing the right thing' can be difficult for participants, their decision-supporters (including nominees), workers and providers when it is unclear what the 'right thing' is.

> *"The lack of clarity on processes impacts everyone and there is always the threat that we will be "punished" in some way for doing the wrong thing when the problem is not that we want to do the wrong thing but that we don't know what the right thing is! I imagine others, like me, are claiming funds from the wrong categories due to lack of understanding and live with the risk that someone will advise we are to be penalised for doing the wrong thing" – Participant[1799]*

To address the current confusion in roles in who should be doing what in helping participants to manage their budget, Navigators should take on responsibility in helping participants to understand, use and manage their budget over time. This would include supporting participants and their decision-supporters (including nominees) to know what doing the right thing looks like, and in building a participant's capability by learning from mistakes. However, the exception would be those who choose to and have the capability to fully self-manage, where the participant or nominee would retain responsibility for managing their budget.

Navigators would also play a key role in making sure providers and workers are doing the right thing, and raise concerns with the NDIA or National Disability Supports Quality and Safeguards Commission if they don't.

Enhancing current payment controls is necessary in transitioning to fully electronic payments

During 2022-23, over 100 million transactions – which represents approximately $34 billion in government expenditure – were processed by the current NDIS payment system.[1800]

The increasing volume of transactions and payments means that, without more sophisticated controls, current leakage or wastage in scheme costs due to non-compliance may be expected to continue - or even grow - as the value and volume of scheme payments continue to rise.[1801]

The transition to fully electronic payments presents an opportunity to substantially enhance current payment controls in parallel. With more data captured for all NDIS transactions, governments would have increased analytical capacity to detect anomalies in individual transactions and spending patterns. More sophisticated payment controls could be designed so that participants and providers could easily resolve and address claiming errors, while ensuring claims - where they need further validation and investigation - go through sufficient assurance before any payment is made.

Further improvements in analytical capacity and capability could also be driven by establishing more effective intergovernmental data sharing agreements (where appropriate). In addition to investing in a National Disability Data Asset (NDDA) (see Action 23.4), greater intergovernmental sharing of data would ensure responses are proportionate to fraud risks, strengthen government fraud controls and deter people who are looking for opportunities to exploit and defraud public funding across government programs and schemes.

Concerted investment and continuous efforts will be required across governments, not just by the NDIA.

3.2.6 Over time, how participants manage their budget and who would support them would change

As part of a fairer and more consistent participant pathway, new assessment processes (see Recommendation 3) should take a person-centred approach and consider the holistic needs of the individual person with disability. Part of this assessment should include:

- understanding what a person needs and wants help with, and how much help they need, to navigate the scheme and NDIS markets. This should consider the person's capability to make decisions and manage budgets, and opportunities to build their skills and confidence to do these activities independently over time.

- considering the potential risks the person may face in navigating the scheme. Assessing risks should also be at the whole-of-person level rather than considering the risks associated with specific supports. Instead, potential risks around the nature of supports and how they are delivered would be assessed and managed through a more risk-proportionate model of provider regulation (see Recommendation 17).

Figure 2: Potential changes over time around how participants might manage their funding

Current NDIS methods of managing funding

NDIA-managing participants	Plan-managing participants	Partly self-managing participants	Fully self-managing participants
Access to registered providers only	Access to registered and unregistered providers		
Subject to price caps		Not subject to price caps	
NDIS payment system pays provider	Plan manager pays provider on participants' behalf	Participant (or, where available, their plan manager) pays on participants' behalf	Participant pays provider and then seeks reimbursement
Access to NDIA Partner or support coordinator	Access to NDIA Partner or support coordinator + Access to plan manager	Access to NDIA Partner + Few may have plan manager or support coordinator for capacity building to self-manage	Access to NDIA Partner

Proposed future NDIS methods of managing funding

Participants who are not self-managing	Fully self-managing participants
Access to registered or enrolled providers, depending on provider activities and operations	
Subject to price caps	Not subject to price caps
NDIS payment system can pay all providers – both registered and enrolled. Participants have a range of channels to pay providers.	
Navigator provides help with monitoring spend and managing funding. • What, and how much, help is provided by the Navigator will vary depending on what participants need or want help with, and the risks they face. • Includes building participants' skills and confidence to self-manage over time, and as needed.	**Navigator is point of contact** • Navigator may provide low level assistance with monitoring spend, where needed

The holistic needs assessment should then inform the new approach to delivering navigation support (see Recommendation 4), which should ensure the level of navigation support is more responsive and tailored to the needs of the person with disability.

For participants and their decision-supporters (including nominees), this means the link between a participant's financial management of their budget and a participant's access to service providers based on the provider's regulatory status is removed. Instead, the level of navigation support would be better matched with the participant's capability, needs, preferences and the risks they face at a whole-of-person level.

Where a participant or their decision-supporters (including nominees) wants to and has the capability to self-manage their budget, they could self-manage their whole budget. Participants and their decision-supporters (including nominees) would no longer have to NDIA-manage or plan-manage parts of their budget as a way to manage risks associated with specific types of supports and how they are delivered.

Participants and their decision-supporters (including nominees) would get help from a Navigator where they need or want help to manage their budget. Navigators should help participants and their decision-supporters (including nominees) with understanding and using their budget. Navigators would also be responsible for helping participants and their decision-supporters (including nominees) to monitor and manage their budget, to remove confusion about who should be doing what.

Participants who want to build capacity to self-manage over time would also get more support to do so. As support from their Navigator is more tailored to their needs, participants' budgets would not have to specifically include a support item for capability building to self-manage as is required currently. Instead, the Navigator should help to build their capability to self-manage their budget based on the activities a participant needs to build skills and confidence in.

Opportunities should be provided for participants to build skills and confidence to manage their budget more independently. Participants should be allowed to make mistakes and learn from experience. However, they would still be able to draw on support from their Navigator as part of the learning experience. Price caps would still apply (see Action 11.1), and this is to ensure participants have appropriate safeguards as they build skills and confidence in negotiating with service providers around how much to pay for services.

Investing in multi-channel digital payment system (see Action 10.3) would support all participants (with help from their Navigator where needed) to pay their providers - whether they are enrolled or registered - through the NDIS payment system. This should mean that, over time, Plan Managers should no longer need to be the 'middle-man' who helps with paying the bills.

This means that digital payment systems and the increased support of Navigators in helping participants manage their budgets would reduce the demand for some functions of plan management. Some Plan Managers who are skilled and experienced in helping participants with tracking spend and managing their budget could possess the necessary capability and competency

to take on Navigator functions, as could some Support Coordinators (see Chapter 2 and Recommendation 4).

However, the transition to the new approach to delivering navigation supports and fully electronic payments will take time. So too would building the scheme's digital infrastructure and capability to tackle scheme integrity issues.

In the interim, Plan Managers still have an important role to play in supporting prevention, detection and response to non-compliance and fraud. A few Plan Managers have reported to us that they have data analytics capability to systematically detect anomalies in transactions or spending patterns.[1802] Plan Managers with this capability could be well-placed to support governments in building the requisite capacity and capability to better protect scheme integrity.

Box 64: What the future for Plan Managers could look like

Over time, as the range of reforms to the NDIS are implemented:

- Plan Managers would no longer have to help participants and their decision-supporters (including nominees) to 'pay their bills or invoices'. Participants and their decision-supporters (including nominees) would be able to pay all their providers - both enrolled and registered providers (see Recommendation 17) – through a multi-channel digital NDIS payment system. This could include tools for participants and their decision-supporters (including nominees) to receive and approve electronic invoices through the NDIS payment system.
- The roles and functions of who is helping a participant and their decision-supporters (including nominees) to understand how to use their budget and to manage their budget would be better aligned, and gradually shift to Navigators (see Recommendation 4). Some Plan Managers who are skilled and experienced in helping participants and their decision-supporters (including nominees) with tracking spending and managing budgets could possess the necessary capability and competency to take on Navigator functions.
- The NDIS digital infrastructure would have strengthened capacity and capability to detect, prevent and respond to non-compliance and fraud. Some Plan Managers who have the data analytics capability could be well-placed to support governments in building the requisite capacity and capability to better protect scheme integrity.

3.2.7 Uplifting the NDIS digital architecture should be well sequenced and aligned with the broader whole-of-government agenda on digital transformation

Changes to the enabling NDIS digital architecture are needed across a number of our recommendations. Development of a centralised online platform, expanding APIs for third party online platforms, transition to a fully electronic payment system and parallel uplift in NDIS systems to protect scheme integrity are only some of many enabling system changes that would be required.

Improvements to the NDIS digital landscape should not happen overnight, and should be coordinated well and communicated clearly and early

Lessons from the NDIA's test of their new business system, PACE, has particularly highlighted the need for system changes to be much better coordinated and communicated to participants, providers, NDIA staff and NDIA Partners.[1803]

An NDIS digital transformation strategy and roadmap is needed to guide improvements and investments to the NDIS digital landscape and information infrastructure. Disruptions to participants, intermediaries and providers should be minimised through early and clear communications about what the changes are and how they would impact participants, intermediaries and providers.

The strategy and roadmap should link with and leverage digital transformation efforts across the Australian Government. This should ensure investments in the NDIS digital landscape support interoperability and data sharing with other Australian Government systems (such as aged care and veterans' care) to minimise the burden placed on participants, workers and providers operating across the care and support sector.

Investments in the digital landscape should also deliver seamless user experience for participants and providers across all government services, not just the NDIS.

3.2.8 Action & Implementation Details

Action 10.3: The National Disability Insurance Agency should transition to fully electronic payments and improve visibility of NDIS payments

This should give governments the information required to be effective market stewards, understand what works and deliver outcomes, and strengthen scheme integrity.

Investments should be made in a multi-channel digital payments approach, including near real-time claims and payment technologies. The design of a multi-channel digital payments approach should:

- make it easier and faster for participants to pay for supports
- improve information captured on all NDIS payments, and
- enable participants and Navigators to better monitor spending (see Action 3.6).

Participants should be able to continue to pay upfront and seek reimbursements in the short term, but reimbursements should be phased out over time.

Implementation detail:

- The NDIA should scope and roll out a new multi-channel digital payment system to replace the current ageing system. This should include, but not be limited to:
  - technology for providers to generate invoices, and for participants to receive and approve, through the NDIS payment system, and

- allowing participants to pay providers at point of support using near real-time claims and payments technology.

- The NDIA should scope the design features and functionality needed to operationalise near real-time claims and payments technology as part of the current NDIS Claims at Point of Support (C-POS) project. The NDIA should work with participants, their families, carers, nominees and service providers including on:

  - where near real-time payments for supports could be easily and safely be operationalised with appropriate payment controls, and

  - what notifications, checks and approvals participants need where there are potentially suspicious payments (such as new payees, payments for services in different jurisdictions at the same time).

- The NDIA should ensure all NDIS payment channels capture all necessary information to steward the market, evaluate what works and protect scheme integrity.

  - As a minimum, all participants and providers should be required to provide information on what and where support is delivered, the cost of these supports, and who delivers the supports. This should be easier for all participants (including self-managing participants) and providers through using digital channels to invoice.

  - A transition period should allow the NDIA to develop and roll out improvements to existing digital payment channels.

  - A transition period should also allow time for participants to understand and adopt new and improved digital payment channels. Over time as electronic payments become easier and faster, self-managing participants should not need to pay for supports first and then seek a reimbursement.

- The NDIA should test near real-time payments technology with participants who are managing their own budgets and those who are self-managing budgets on behalf of participants. Learnings from early testing should inform the rollout to all participants.

Action 10.4: The <u>Australian Government</u> should invest in the underpinning digital infrastructure and capability needed to protect the integrity of the NDIS

Investments in information technology, capacity and capability should be made to improve prevention, detection and responses to non-compliance, sharp practices and fraud in the scheme. Where possible, existing fit-for-purpose government technologies should be reused or built upon.

Investments should align with the Australian Government's future Data and Digital Government Strategy, and form part of a holistic approach in protecting the integrity of the scheme and the broader NDIS digital transformation strategy and roadmap (see Action 10.6).

Action 10.5: The Australian Government should develop and implement a clear transition path for existing Plan Managers

The future electronic payment system (see Action 10.3) would enable participants to pay all registered and enrolled providers. A strategy to steward the plan management market should be developed in transitioning to fully electronic payments.

Work to clarify Plan Managers' current responsibilities in protecting scheme integrity should start now and be refined as the NDIS digital infrastructure and capability evolves (see Action 10.4).

Where needed, support for participants to monitor and manage their budget should transition to Navigators (see Recommendation 4).

Implementation detail:

- The NDIA and new National Disability Supports Quality and Safeguards Commission should work together to enforce current responsibilities and expectations of Plan Managers in protecting scheme integrity. As a priority, the NDIA should improve incentives for Plan Managers to proactively raise scheme integrity concerns and have processes and resources in place to respond quickly.
- The Department of Social Services should develop legislative amendments to give effect to changes in the current financial management methods, as part of making it easier to pay providers (see Actions 10.3 and 17.1) and under the new Navigator model (see Recommendation 3).
- The NDIA and new National Disability Supports Quality and Safeguards Commission should signal early any changes to plan management to minimise disruptions and transition costs for participants, workers, providers and the broader market.

Action 10.6 The Australian Government should design and roll out an NDIS digital transformation strategy and roadmap to bring together and sequence all initiatives in the NDIS digital landscape

This should guide improvements to the NDIS digital landscape, support a more risk-proportionate regulation of providers, and enable a seamless user experience for participants, providers and workers.

The strategy and roadmap should link with and leverage digital transformation efforts across the Australian Government. This should ensure investments in the NDIS digital landscape support interoperability and data sharing with other Australian Government systems (such as aged care and veterans' care) to minimise the burden placed on participants, workers and providers.

Implementation detail:

- The NDIA and new National Disability Supports Quality and Safeguards Commission should coordinate investment and efforts in digital infrastructure for payments processing and scheme integrity. Investments in new payments systems should be done in parallel with investments in technology and capability to strengthen identity verification, as well as prevention and detection analytics (such as fraud detection profiles, payment controls, validation processes).
- The NDIA and new National Disability Supports Quality and Safeguards Commission and should build the digital infrastructure and analytical capability needed to implement a more risk-proportionate model of regulation (see Action 17.1). Efforts and investments in digital infrastructure should leverage existing government information technology (such as myGovID) and ensure interoperability between the enrolment and registration processes and payment systems.
- The NDIA should work with the new National Disability Supports Quality and Safeguards Commission and Australian Government agencies to enable faster and more secure data sharing arrangements to safeguard participants and protect scheme integrity. Data sharing arrangements should ensure participant privacy is protected, and that their information is stored and handled appropriately, while ensuring timely sharing of information on providers and workers across the care and support sector for compliance purposes.
- The NDIA should work with the new National Disability Supports Quality and Safeguards Commission and Australian Government agencies to identify opportunities to share data for monitoring and measuring participant and scheme outcomes as part of any data sharing arrangements. This should inform improvements in data collection, analysis and reporting on outcomes (see Recommendation 23).

4. Payment and pricing frameworks to improve incentives for the delivery of quality supports

- How providers are paid, and how much they are paid, for delivering supports shapes the incentives for how providers behave and deliver supports to participants in NDIS markets. To date, governments have largely used a fee-for-service payment approach and price caps to attract 'efficient' providers into NDIS markets to meet demand.
- A fee-for-service payment approach is an easy way to pay providers, but may encourage providers to behave in ways that don't deliver value or outcomes for participants. Importantly, a fee-for-service approach may also discourage providers from building participant capacity and connecting participants to their community as the participant would need less supports.
- Most NDIS supports have a price cap. Price caps aim to prevent large providers from using their market power to drive up prices and help ensure services are value for money. But the blunt and opaque way in which price caps are set is not working. It can be hard for providers to

respond to participants' needs, invest in workforce capability, and to encourage quality and innovation. It can also be difficult for participants, families and carers to find supports below the price cap. There are also unintended consequences for participants with complex support needs, in different locations and for supports in group settings.

- Yet, removing price caps would likely lead to increased scheme costs without an associated improvement to outcomes for participants, placing pressure on scheme sustainability.

- Instead, the focus should be on underpinning market reforms that help align incentives for participants, providers and governments. This should include a new pricing and payments framework, which should have four key elements:

  - Strengthened financial reporting and information from providers to inform how prices are set and how payment approaches are working.

  - A mix of pricing and payment approaches that reward providers for delivering quality supports for participants. A fee-for-service payment approach may still be appropriate for some supports (such as capital) but governments should better leverage their buying power.

  - Improve transparency, predictability and alignment of NDIS price setting processes by transitioning the responsibility for advising on NDIS price settings to the Independent Health and Aged Care Pricing Authority (IHACPA).

  - Dynamic feedback mechanisms that both feed into, and draw from, the shift to a fully electronic NDIS payment system, better ways to monitor spend and manage funding, new budget setting processes, and more active, evidence-driven market monitoring.

- Governments will also need to review and refine the new pricing and payments framework once underpinning reforms have been implemented. This should ensure the pricing and payments framework remains suitable with how changing conditions in NDIS markets.

Recommendation 11: Reform pricing and payments frameworks to improve incentives for providers to deliver quality supports to participants

📄 Legislative change required

- 📄 Action 11.1: The <u>Department of Social Services </u>should develop a new NDIS pricing and payments framework to be administered by the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority, including better ways to pay providers to promote the delivery of efficient and quality supports and continuity of supply.

- Action 11.2: The <u>National Disability Insurance Agency</u> should progressively roll-out preferred provider arrangements for capital supports to better leverage its buying power and streamline access for participants.

- 📄 Action 11.3: The <u>Australian Government</u> should transition responsibility for advising on NDIS pricing to the Independent Health and Aged Care Pricing Authority to strengthen transparency, predictability and alignment.

- Action 11.4: The <u>Australian Government</u> should review and refine the pricing and payments framework once underpinning reforms have been implemented.

4.1. There are opportunities to improve NDIS pricing and payment approaches

When well-designed, market-based approaches for social services – where participants have choice and providers compete – can foster innovation, lower the cost of service delivery, and improve the quality of supports and participant outcomes.

Realising the benefits of a market-based approach, however, requires that scheme settings align incentives for participants, providers and government. Decisions around pricing and payment approaches are key to ensuring incentives for providers align with the interests of participants and governments.

Decisions about price settings need to consider the market dynamics - including the needs and characteristics of participants, providers and the nature of supports. NDIS markets are not like other markets. For example, finding and buying NDIS supports is very different than shopping for groceries at the supermarket. Prices don't perform the same function for participants in selecting NDIS supports in the way they do when people go grocery shopping.

While price settings are important, how the NDIA (as the funding body) pays providers also matters. How providers are paid shapes how providers deliver supports and behave in NDIS markets. The interplay between pricing and payment approaches has a critical role in what supports are supplied to the market and the outcomes achieved for participants.

The market-based model in the scheme is centred on a pricing and payment approach which includes fee-for-service payments and capped prices for supports (Figure 119).

Figure 3: The NDIS pricing and payment approach

The blunt and opaque way in which the current NDIS pricing and payment approach has been set and applied has not effectively aligned incentives for participants, providers and governments to support NDIS markets in functioning well.

4.2.   A range of payment approaches are needed to improve incentives for providers to deliver quality supports

NDIS markets operate largely through a fee-for-service payment approach, where providers are paid for each unit of service - typically, the number hours of supports they deliver. But other payment approaches can better align the incentives for providers with the interests of participants and governments.

4.2.1   A fee-for-service payment approach rewards providers for higher levels of activity rather than investing in the capability of participants

The fee-for-service approach is easy to administer and understand. However, it rewards providers for the volume of supports they deliver, regardless of the 'value' or benefit for participants.

> *"Currently providers are paid based on the services they provide, rather the benefits of those services to participants. Providers should be rewarded for helping to achieve participant goals. This would benefit the providers who provide high-quality services, and it increases the focus for Government, the NDIS and providers on building the long-term capabilities of participants." – Get Skilled Access[1804]*

The fee-for-service approach has not promoted quality, can stifle innovation and does not always deliver value-for-money. Under this approach, providers have financial incentives to maximise and maintain the volume of supports, regardless of the level of participant need or benefit of the supports. For example, providers may not benefit when they help a participant to build capacity and be more connected to community as the participant would need less supports.

> *"Fee-for-service arrangements may also contribute to a lack of investment in provider and workforce capability and quality assurance. Where providers are incentivised to prioritise more services over and above quality assurance, people with disability bear the consequences. This includes funding consequences (through over-servicing) and safety and quality consequences (as providers are incentivised to limit resources)." – Women with Disabilities Australia[1805]*

Inherent friction also exists between the fee-for-service payment approach and the investment principles of the scheme. Fee-for-service encourages higher levels of activity and short-term transactional relationships in service delivery, rather than rewarding providers for investing in the capability of participants to reduce their ongoing needs for formal supports. This can place pressure on the total cost of the scheme.

> *"It may be tempting to think that increased spending is always a good thing for people with disabilities; but we should also be very cautious of treating the size of the NDIS as a good measure of how well the NDIS meets people's needs. It is quite possible for costs to increase without any benefit to the person. The price of a service does not determine the quality of a service; many costs are hidden from view and cost increases can be symptoms of waste, duplication or too much bureaucracy." – Dr Simon Duffy*

and Dr Mark Brown, commissioned by Disability Advocacy Network Australia (DANA)[1806]

Providers may induce or increase demand for their supports, even when the supports do not represent value-for-money or improve participant outcomes. Incentives for providers to induce demand can be elevated in the NDIS, since participants' budgets are fully government-funded and there is considerable inconsistency and gaps in expectations stemming from what is 'reasonable and necessary' (see Chapter 2).

Incentives for providers to induce demand can be further compounded where participants rely on the advice of their providers about what level of supports and services is beneficial. Providers could have more financial incentives to recommend additional supports that may not be essential to participant outcomes. Current lack of accountability further increases the incentives to induce demand as there are few requirements or expectations around reporting participant outcomes, or demonstrating the value of supports that are being delivered.

Relying on fee-for-service payments as the main payment approach can also get in the way of delivering 'value-based' supports. For example, international research suggests value-based healthcare – which place "value and values at the centre" – can help ensure people "receive the care that can provide them with outcomes they think are important and that limited resources are focused on high-value interventions".[1807] In rewarding providers for the volume of supports they deliver, fee-for-service displaces value and the values of participants from being at the centre of the supports being delivered.

4.2.2 Shifting away from one-size-fits-all, fee-for-service payments in the NDIS

While it is a common way to pay providers of social services, fee-for-service is not the only way.

There are other payment approaches that are used across different social markets (Figure 120). Each payment approach has advantages and disadvantages and rewards different kinds of provider behaviour.

> *"... there is no silver bullet payment reform that will address all issues in the system. Tradeoffs are inherent to all funding models, with no one single reform likely to meet all reform objectives. Reform is iterative and critically must be enabled by stakeholder engagement and systems. – National Disability Services[1808]*

Given the diversity and nature of NDIS supports, a range of different payment approaches should be used to align incentives for providers with participants' and governments' interests, and in doing so, optimise value for participants and the scheme.

Figure 120: Each payment approach has advantages and disadvantages [1809]

Options	Advantages	Disadvantages
Block funding Lump sum payments covering specific services for a set period of time (*Characteristic of pre-NDIS funding models*)	• Expenditure is predictable • Easy to administer • Adopting innovations does not impact providers' budgets • Appropriate when market intervention is needed to ensure supply (e.g. bulk purchasing)	• Incentive to underprovide services to reduce workloads • More limited incentive to improve quality of service • Limited accountability in how payments are spent • Better providers attract more work but not necessarily more resources • Limited support for user choice and individualisation of response • Reduced incentives for efficiency over time
Fee-for-service Reimbursement for each unit of service provided	• Can support user choice • Incentive to provide services to more people • Incentive to provide services regardless of costs	• Incentive to increase activity and over-service users • Incentive to limit or reduce resources allocated to users • Few incentives to work with other providers or build social and community capital • Limited incentive to innovate services • Funder bears financial risk of increased demand
Enrolment (capitation) Period lump-sum payments for each enrolled user	• Expenditure is predictable • Incentive to provide preventative services • Incentive to reduce costs and innovate services • Can encourage coordination between providers	• Incentive to decrease activity and under-service users if service and quality are not well monitored and enforced • Incentive to shift service delivery to other providers • Incentives to cherry-pick participants if not risk weighted • Little incentive to increase quality/quantity of services
Outcome-based payments Rewards or penalties based on meeting certain metrics	• Incentive to undertake beneficial services that would otherwise not be remunerated • Can aid consistency in meeting quality standards	• Significant monitoring effort required • Indicators hard to define and/or may not link to outcomes or be in provider's control • Can be high compliance costs for providers • Risk of unintended provider behaviour in order to achieve an outcome • May be little incentive to improve beyond targets

Activity-based payments are a form of fee-for-service, but they cover a defined group of services provided (or an 'activity'), rather than each individual service.

Activity-based payments are used to pay residential aged care providers under the Australian National Aged Care Classification (AN-ACC), which was introduced in October 2022. Activity-based payments are also used in Australia's public hospital system, to pay for a group of services. For example, in a hospital this may include the costs of accommodation, surgery, pathology, nursing

and medicines for an episode of care. When compared to a fee-for-service payment, activity-based payments strengthen incentives for providers to reduce costs. Activity-based funding, however, can be more complex to administer, relies on standardisation of inputs and requires more detailed data.

Beyond variations on fee-for-service, such as activity-based payments, introducing different payment approaches could help ensure the service offering of providers better reflects the nature of supports. In a 2020 report, the Medicare Benefits Schedule (MBS) Review Taskforce suggested the fee-for-service model used for a wide range of MBS items should be complemented by alternative funding models to encourage more efficient, coordinated care with a greater focus on preventative health and better management of chronic conditions to deliver improved outcomes for patients.[1810]

For example, enrolment payments are where participants 'enrol' with a provider for a period. These could be used where support needs are more predictable and less episodic in nature. This could strengthen the focus on providers' relationships with participants and encourage them to invest in participants' capability. Careful design would be required to mitigate the risk of poor outcomes under enrolment approaches. This includes careful monitoring and feedback loops to address the risk of providers limiting access to certain services required by participants, choosing to only provide services to participants with less complex needs, or under-servicing.

> *"… enrolment models are ideal where there is large potential for prevention (such as, of chronic disease) and significant over servicing in the market under fee-for-service arrangements. Enrolment models encourage providers to minimise input costs. Efficiency gains are captured by providers, not payers, and quality standards are needed." – National Disability Services[1811]*

4.2.3   Considering new ways to pay for psychosocial disability-specific supports

As outlined in the Chapter 2, the Review recommends a new approach to delivering psychosocial supports in the scheme, including developing an early intervention pathway for psychosocial disability (see Action 7.2).

In designing the early intervention pathway, consideration should be given to a mixture of payment approaches, including enrolment, activity-based, fee-for-service or blended payment approaches.

Payment methods should encourage the use of evidence-based supports, recovery-oriented approaches and capacity building. For example, enrolment payments may be suitable for early-intervention psychosocial supports being provided over a period of time, as this could incentivise providers to focus on building participants' capability and skills.

As part of its broader work on advising on NDIS pricing (see Recommendation 11), IHACPA, working with other government agencies, participants and the broader sector, should consider the appropriateness of different payment approaches for psychosocial supports (see Action 7.4).

4.2.4 Outcome-based payments can be effective when well designed

Paying for outcomes in the NDIS could strengthen incentives for providers to deliver evidence-based and timely services.

> "... outcomes-based payments are most likely to achieve the objective of aligning provider incentives with participant outcomes. Instead of focusing on the quantity of services delivered, providers are rewarded based on the positive outcomes achieved by participants. This approach encourages providers to deliver high-quality and effective services, as their reimbursement is contingent on the success of their interventions." – Provider[1812]

> "Performance incentives can drive improvements in outcomes, especially when incentives are aligned with consumer and funder outcomes." – National Disability Services[1813]

> "Outcome payments are an attractive idea because they are a good way for the steward to give a clear signal about what is wanted from the market/community." – JFA Purple Orange[1814]

The NDIA's 2018 Independent Pricing Review, conducted by McKinsey & Company, suggested that over the long term the development of a competitive marketplace should enable changes to the scheme's current model of using price caps and fee-for-service payments. The report recommended trialling outcomes-based pricing in the NDIS.

> "Firstly, the NDIA should conduct a trial of outcomes-based pricing. This is an appealing alternative to input-based pricing as it encourages providers to maximise outcomes, rather than the volume of services provided. However, it is significantly more complex and requires strong baseline data and measurement systems. A trial would provide valuable learnings on how this approach might be implemented in some supports." – McKinsey & Company, NDIA Independent Pricing Review[1815]

The Review also heard from participants, carers and families who called for a greater focus on participant outcomes.

> "All service providers should be accountable for the services they are providing. They should demonstrate a positive outcome for the clients and work with the families to achieve sustainable changes. I agree with comments about the performance of provider needing to be measured and rated and more focus on the outcomes being achieved for the child rather than how many service visits (the current focus seems to be on the NDIS funding)." – Carer[1816]

Outcome-based payments have been used in other social services. For example, employment service providers are paid in part for supporting people to achieve employment outcomes. Participants in mainstream and Disability Employment Services can also choose their provider on

the basis of the provider's past outcomes or performance via a 'star rating'. In addition, under the previous Jobactive scheme, higher performing employment providers were allocated a larger market share every 18 months, while poorer performing providers lost market share. For these to be effective, it is essential that outcomes are clearly defined and unable to be gamed.

Experience in other social services has shown that providers can be responsive to outcome-based payments, which can drive benefits for participants.

Case Study 23: An evaluation of the New South Wales Family Preservation Service highlighted some of the benefits of payment-by-results

The New South Wales Family Preservation Service program supports children at risk of entering out-of-home-care by providing a range of supports including therapy, social work and personal care services. An independent evaluation of the program in 2020 found the payment-by-results approach reduced entry to acute settings. The evaluation also found material cost savings with higher uptake of preventative actions. Clients with high and complex needs were found to benefit most.[1817]

Case Study 24: Overseas experience also suggests outcome-based payments can lead to improved care

As noted by National Disability Services in its submission to the Review, the French Government achieved significant improvements across a number of medical care domains through a program of financial incentives for physicians who met targets related to health quality indicators.[1818] For example, between 2012 and 2015, the follow-up of chronic disease increased from 50 per cent to 61 per cent and prevention activities increased from 35 per cent to 42 per cent.[1819]

However, it can be difficult to link outcomes to provider performance, and this may be even more challenging in the disability sector. It can take time and long-term commitment from providers to support participants to achieve outcomes, particularly for supports that build participants' capacity. In addition, some supports, such as therapy supports, may sometimes relate to the maintenance of capacity, rather than improvements in capacity.

> *"The NDIS would need to ensure that 'outcomes' included everyday life outcomes, such as maintaining physical and mental health. 'Outcomes' and 'goals' should not be limited to objectives to be completed or accomplished between plan dates or within service agreements … determining 'outcomes' or 'goals' must take into account a person's life, limitations, strengths, and the fluctuations of their disabilities." – Women with Disabilities Australia[1820]*

Providers may not wish to supply supports to participants if too much of a payment is 'at risk', that is, if too much of a payment is based on achieving an outcome.

It is important that outcome-based payments are carefully designed to avoid providers 'cherry picking' participants. This could include ensuring outcome-based payments are risk-weighted for the additional costs of supporting participants with more complex support needs, and that any adjustments for risk are based on factors that cannot be manipulated by providers.

Any outcome payments should be designed in such a way to ensure outcome measures cannot be 'gamed' by providers, who may otherwise be perversely incentivised to seek only short-term outcomes that do not help participants in the longer term.

> *"There is a risk that use of outcomes may create perverse incentives to cherry pick clients by unscrupulous operators, potentially excluding clients with complex needs, clients with low prospect of employment or independent living, or clients who have who have difficulty engaging with services … leaving clients with more complex disability or needs without support." – Occupational Therapy Australia[1821]*

> *"However, the NDIS should be cautious of an outcomes-based approach that rewards or penalises providers on the basis of specified metrics. This approach may incentivise providers to 'cherry pick' participants who are considered more likely to achieve certain outcomes. Further, outcomes-based approaches could lead to providers refusing to continue to support participants where they are unable to achieve pre-determined outcomes due to changes in their circumstances. This poses significant risks for participants and their continued access to quality supports." – Women with Disabilities Australia[1822]*

> *"While holding providers accountable for delivering impact is essential, such an approach is not without its challenges. It is possible for a high-quality provider to work hard on behalf of a participant and still not achieve the intended outcome because of forces that may be largely outside their control. As a result, outcome payments could deter providers from offering supports to participants they perceive to have more complex needs or circumstances … These unintended consequences will need to be carefully navigated when considering a framework of outcomes payments." – JFA Purple Orange[1823]*

One way to do this could be measuring outcomes by the 'inputs', or the mix of inputs, that drive quality delivery and outcomes. For example, workforce is one the underpinning 'structural inputs' of the three core domains for quality aged care. Workforce attributes that directly contribute to the outcome of quality aged care, including staffing levels, skill mix and staff turnover levels, could be collected and used as indicators to measure outcomes.[1824] In this way, providers could have more incentives to deliver quality supports which drive outcomes, compared to a fee-for-service payment approach which rewards on the volume of services delivered.

In order to drive positive outcomes for participants, providers require the necessary scope to work with participants to design and facilitate change over time, in a way that reflects their goals and the

objectives of the supports. To affect an outcome, providers may need to be able to offer a 'bundle' of 'wrap around' supports.

4.2.5 Blended payment approaches could better align incentives between participants, providers and governments

Paying providers a 'blended' payment' - that is, based on a mix of payment approaches - could help balance the advantages and disadvantages of particular payment approaches and better align incentives between participants, providers and governments.

> *"... a blended payment approach would allow government to realise cost efficiencies in parts of the market with low scope for innovation and with relative market depth and maturity while utilising other payment models such as bundling and incentives to drive quality improvements in other subsets of the system."* – National Disability Services[1825]

Well-designed blended payment approaches could put a greater focus on participant outcomes without relying wholly on a pure outcome payment. For example, enrolment arrangements, when blended with outcome-based payments, can incentivise providers to reduce costs through providing fewer, or less costly, supports and investing in cost-effective preventive and early intervention services.

> *"Blended payment models would allow participants to pay providers in another way instead of only fee-for-service, for example paying more for a provider who can demonstrate high quality service delivery."* – Get Skilled Access[1826]

Any blended payment approaches would benefit from a carefully designed and nuanced outcomes framework that measures whether providers are delivering positive outcomes for participants (see Recommendation 23). This would take considerable time to 'get right' but is essential, as any model which pays for outcomes will drive providers to deliver those outcomes, whether they are optimal or not.

Blended payment approaches are also being considered in other social services in Australia. For example, the 2022 Strengthening Medicare Taskforce Report found "introducing more blended funding models alongside fee-for-service will support primary care sustainability and foster innovative models of primary care in rural and remote communities".[1827] It also recommended the Australian Government "support general practice in management of complex chronic disease through blended funding models integrated with fee-for-service, with funding for longer consultations and incentives that better promote quality bundles of care for people who need it most".[1828]

> ### Case Study 25: Blended funding models to support wrap around primary care for frequent hospital users
>
> The Australian Government's *Strengthening Medicare Policies* include an initiative to offer wrap around primary care for frequent hospital users to improve access to comprehensive clinical

care and support self-management for people with chronic conditions. The Australian Government will design and implement this model of care to support general practices through a blended funding model linked to MyMedicare to work in primary healthcare teams. The intent of this initiative is to reduce the burden on stressed hospital emergency departments, while improving patient access, experience and health outcomes.[1829]

Case Study 26: Overseas experience suggests enrolment models can promote delivery of 'value based' supports

An enrolment 'matrix' system for a knee or hip arthroplasty[1830]

A 'matrix' of enrolment payments was introduced in a United States community hospital system, with procedures categorised based on technological sophistication and cost. In the first year after the implementation of the matrix system, implant costs for the hospital decreased by 23 per cent per implant for knee procedures and 17 per cent per implant for hip procedures.

Exhibit 1: Change in target average price before and after introduction of capitated system
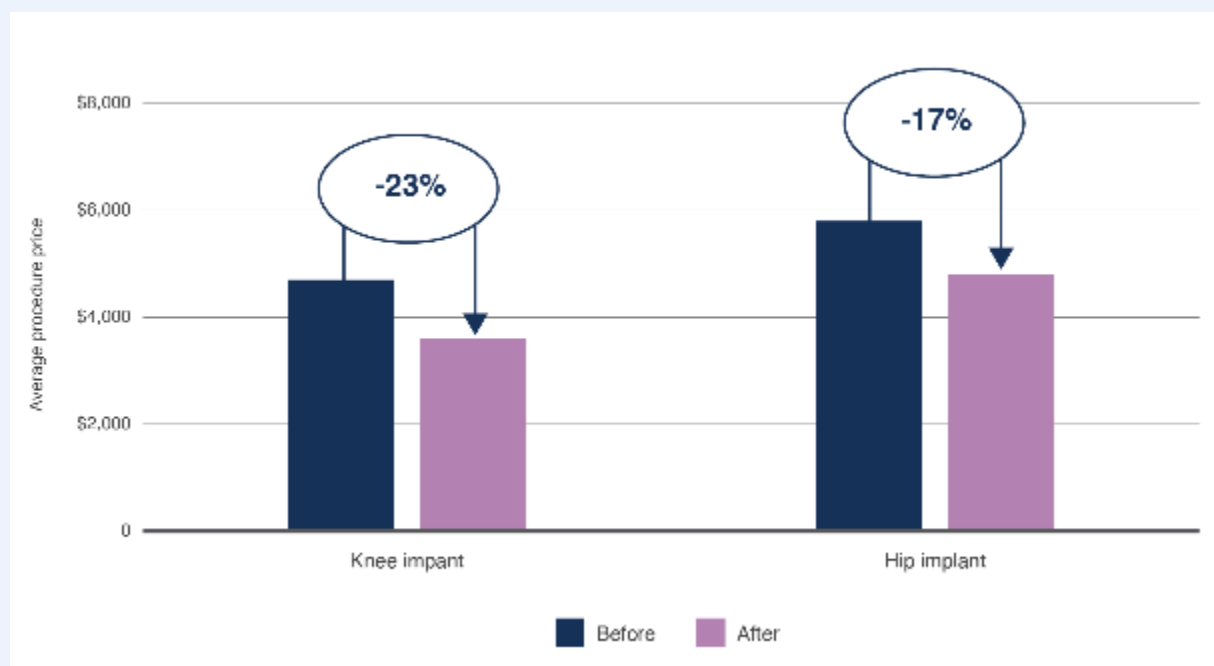
Improved preventive care for Swedish public dental subscription agreements[1831]

Patients were given the option to enter a risk-weighted subscription (capitation) plan with a three year enrolment period as an alternative to fee-for-service plans. Those who chose to enter a subscription agreement received 66 per cent more preventive care, and had on average better oral health than those who entered a purely fee-for-service plan.

Exhibit 2: Proportion of clients receiving additional preventive care
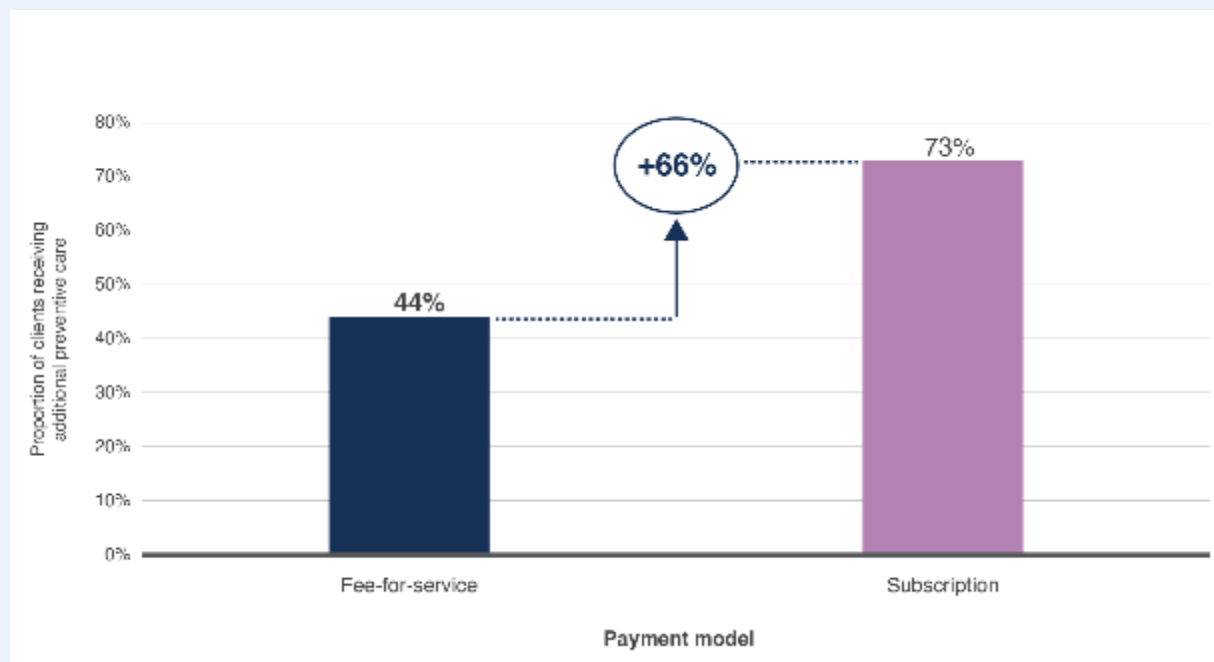
Enrolment approaches have been found to reduce healthcare costs and improve outcomes[1832]

Researchers in the United States evaluated the cost of care for Medicaid patients with severe mental illness. They found an enrolment model with a for-profit element was more cost-effective than the fee-for-service model or the not-for-profit enrolment group.[1833]

It is notable that all of these examples are from the health system, where it is simpler to measure outcomes than in the social model of disability, where many factors can contribute to outcomes, not just those interventions or supports which are being measured. This implies the need for a cautious and careful approach to outcome-based or blended payment models in the context of the NDIS, starting in areas or supports where outcomes are clearest.

4.2.6   Trialling blended payment approaches

In May 2023, the Australian Government announced $24.6 million to trial blended payments in the NDIS. The trials will be undertaken in two areas:

- school leaver employment supports (SLES) to "identify ways to improve employment outcomes for participants"
- moving young people in residential aged care (YPIRAC) "to more appropriate housing with supported independent living (SIL) to drive innovative services delivery approaches".[1834]

DSS and the NDIA will work with participants and providers to co-design and trial blended payment models, to increase incentives for providers to innovate service delivery and improve outcomes for NDIS participants. Participation in the trials will be voluntary for participants and consultation work is expected to begin in late 2023.[1835]

"An appropriate next step for government would to be trial new approaches in smaller programs with defined services and invest in evaluating these, as appears to be planned with SLES and younger people living in aged care settings. Taking a co-design approach where people with a disability who have used, or currently use, these types of services will be an important part of this process." – Inclusion Australia[1836]

The Review's recommended new funding approach for 24/7 living supports (see Action 9.2) will see the introduction of a blended payment model, with providers of 24/7 living supports paid an enrolment payment and potentially, in time, a small outcomes based payment, once there is a better understanding and effective measurement of good outcomes.

4.3. Appropriate price settings are critical for market development and participant outcomes

Price settings are the rules and processes around how much providers can charge participants for delivering supports. They aim to prevent large providers from using their market power to drive up prices and help ensure services are value for money.

However, the way price caps are set is creating issues in NDIS markets. The process for setting price caps in opaque. The blunt application of price caps is not helping providers respond to the needs of participants, invest in building workforce capability nor encourage market confidence or innovation. They are also creating unintended consequences in some NDIS markets.

4.3.1 Price caps are the main tool used to set prices in NDIS markets

The NDIA has responsibility for setting maximum prices – or price caps – for NDIS supports.

In setting price caps, the NDIA has stated its intent has been to encourage growth in supply while driving efficiency, and ensuring participants receive value-for-money supports.[1837]

Box 65: How are prices set in the NDIS?

Who sets price caps?

The NDIA Board has final authority for setting price caps.

- The NDIA's Pricing Arrangement Reference Group provides advice, through the NDIA CEO, to the NDIA board on price control arrangements for the NDIS. The group is chaired by an NDIA staff member (the Scheme Actuary) and includes four independent members.[1838]

The NDIA conducts an Annual Pricing Review (APR) to set the prices for different supports.[1839]

- Price caps are published in *NDIS Pricing Arrangements and Price Limits* documents. New price caps typically come into effect on 1 July each year.
- Price caps are identified for a specific unit of supports – such as per hour of assistance with personal domestic activities, self-care activities, or household tasks.[1840]

How are price caps structured?

Prices caps can differ based on the day of the week (weekday or weekend), time of day (during the day or overnight) and public holidays.

Some price caps also differ depending on whether a provider is eligible for a Temporary Transformation Payment (TTP) loading. [1841]

- The TTP was introduced in July 2019 to assist providers to transform their businesses in the move towards a more competitive marketplace.
- To be eligible for the TTP, providers are required to meet conditions set by the NDIA, which previously included participating in annual Financial Benchmarking Surveys.
- The TTP loading was designed to reduce over time. The TTP loading was 7.5 per cent upon its introduction in July 2019 and was reduced to 3.0 per cent from July 2022 and 1.5 per cent from July 2023. The TTP loading is scheduled to end from July 2024.

Additionally there is:

- an approximately 8 per cent loading for high intensity supports provided by disability support workers to participants with complex needs[1842]
- a 40 per cent loading for supports delivered in remote areas
- a 50 per cent loading for supports delivered in very remote areas.

But price caps are not the only price controls used in the NDIS. Price controls also include 'billing rules' as well as conditions on 'quotable supports'. For 'quotable supports', participants are required to submit quotes to the NDIA for approval (Figure 121).

Figure 121: Where price controls are applied in the NDIS[1843]

No price regulation for self-managed participants

12.5% of the total value of supports in 2022-23

No price caps or quotation requirements apply for self-managed participants when using registered or unregistered providers.

Self-managed participants (or their nominees) are assumed to have the capacity to act as informed consumers.

Price caps

82.6% of the total value of supports in 2022-23

For agency- and plan-managed participants, price caps apply to most supports. A price cap is the maximum amount a provider is allowed to charge agency- and plan-managed participants for a particular support.

Price caps apply regardless of whether agency- and plan-managed participants are using registered or unregistered providers.

Therapy supports, assistance with daily living, community participation, supported independent living (SIL) and specialist disability accommodation (SDA) are examples of supports that are subject to a price cap.

Quotes

2.9% of the total value of supports in 2022-23

For agency- and plan-managed participants, quotes are required for many high value, highly differentiated supports. Quotes are subject to approval by the NDIA.

Assistive technology (AT) valued at over $15,000 and home modifications valued at $20,000 or more are examples of supports where quotes are required.

No price caps or quotation requirements

2.0% of the total value of supports in 2022-23

For agency- and plan-managed participants, some low cost or highly variable supports (commonly offered in well-developed markets) are not subject to price caps or quotation requirements. Instead, providers and participants agree on a price for the support.

Consumables, participant transport, assistive technology valued at $15,000 or less and home modifications valued at less than $20,000 are examples of supports that do not have a price cap and do not require quotes.

Most NDIS supports are subject to a price cap. In 2022-23, around 83 per cent of payments were subject to a price cap.[1844]

Price caps were meant to support the scheme during the early stages of market development. The intention was to prevent any large providers from using their market power to drive up prices, while also improving efficiency and ensuring scheme sustainability.[1845]

> *"During transition, price controls are in place to ensure that participants receive value for money in the supports that they receive. In the short to medium term, price controls are required for some disability supports because the markets for disability goods and services are not yet fully developed. The longer-term goal of the NDIA is to remove regulatory mechanisms from the markets for disability supports." – NDIA*[1846]

Ten years on from the roll-out of the scheme, price caps have continued to be the primary tool used by the NDIA to steward the market and drive 'cost efficient' service delivery.

The blunt and opaque way in which price caps are set and applied is not helping providers respond to the needs of participants or encouraging market confidence or innovation. Price caps have not been used to signal other market development priorities such as quality, evidence-based models of care, accountability for outcomes, or achievement of participant goals over time.

4.3.2 Most price caps are set based on an estimate of the 'cost of service provision', typically for the lowest-cost providers

The NDIA typically undertakes an annual Financial Benchmarking Survey, where it collects information on providers' operating costs. In March 2023, the NDIA announced it would not run a 2022-23 NDIS Financial Benchmarking Survey, which it suggested was "due to the NDIS Review and the extensive financial benchmarking work conducted by the NDIA over the last six years".[1847]

The NDIS Financial Benchmarking Survey provides only a limited, and potentially biased, understanding of prices and costs. The 2021-22 NDIS Financial Benchmarking Survey had a response rate of around 15 per cent.[1848] Surveys from 2018-19 and earlier were limited to providers who claimed the Temporary Transformation Payment (TTP), where responding to the survey was previously a requirement to receive the TTP. Since 2019-20, the survey has been opened to all NDIS providers and not just those who claimed the TTP.[1849] However, responses continue to be dominated by TTP recipients, with 83 per cent of respondents to the 2021-22 Financial Benchmarking Survey receiving a TTP.[1850]

For supports delivered by disability support workers, price caps are informed by Financial Benchmarking Surveys and the estimated cost for the lowest-cost 25th percentile of providers in each of four metrics, plus a small margin.[1851] This means, for the given price cap for disability support workers, less than one in four providers face costs less than the price cap.

This approach was largely intended to help shape the NDIS market by rewarding the most efficient providers while the market developed and stabilised in the short term.[1852] Over time, competition was expected to drive provider efficiency.[1853]

The approach used by the NDIA sets the 'efficient' or 'benchmark' cost for disability support workers at a lower point than some other social services. For example, the 'efficient cost' for funding public hospitals, or the Nationally Efficient Price, is based on the *average* cost of an episode of care provided in public hospitals.[1854]

The 2023-24 Disability Support Worker (DSW) Cost Model assumes a corporate overhead cost of 12 per cent, which is meant to cover costs associated with running the administrative side of a business, including accounting, human resources, legal, marketing, and technology functions. It also assumes a profit margin of 2 per cent.[1855] These respective percentages of corporate overheads and profit margins are paid to providers regardless of the outcomes they deliver for participants.

Comparatively, a 2022 report by Social Ventures Australia and the Centre for Social Impact found the average 'indirect costs' or 'overheads' of not-for-profit providers analysed was 33 per cent of the total costs.[1856]

Figure 122: Price caps and the DSW Cost Model[1857]

Price caps and the DSW Cost Model

When setting price caps, the NDIA makes a bottom-up estimate of the cost for a disability support worker (DSW) to estimate the 'fully-loaded cost' of delivering an hour of support based on the following factors:

Time spent with participants *(assumption not stated in 2023-24 DSW cost model)*
The time spent with participants, or 'utilisation rate' is the assumed wages for the time workers spend with participants relative to the time spent on non-billable activities – including time spent on training, breaks and client related administration.

Supervision ratio *(assumption not stated in 2023-24 DSW cost model)*
The 'span of control' is the ratio of workers per supervisor.

Share of casual workers *(assumption not stated in 2023-24 DSW cost model)*
'Permanent employment rate' is the proportion of workers employed on a permanent basis.

Corporate overheads *(12.0% of direct costs in 2023-24 DSW cost model)*
Administrative costs including the accounting, human resources, legal, marketing, and technology functions.

Profit margin *(2% of direct costs in 2023-24 DSW cost model)*

We heard from service providers, peak provider organisations and unions that the DSW Cost Model does not sufficiently account for the costs associated with delivering supports.

"The NDIA Cost Model that informs the pricing of core supports is fundamentally flawed. A number of the original assumptions that underpin the NDIA Cost Model do not reflect market data (e.g. overheads/operating expenses, salary, workers compensation costs), or make projections about performance which are, at best, based on estimates drawn from a broad service and client base which are not comparable. Consequently, the sector is forced to fund the gap to cover the full cost of an hour of support." – The Ability Roundtable[1858]

"The price model does not recognise the time needed to deliver quality services to NDIS participants. DSW's have inadequate time to build relationships with participants, follow up on participants' needs, coordinate and communicate with supervisors and other workers, complete paperwork, debrief and handover between shifts. This results in low quality of care." – Australian Services Union[1859]

4.3.3   Price caps that are set too low can impact provider viability

It is difficult for price caps to be responsive to market changes. But if price caps are set too low, they can impact provider viability.

For example, if price caps are too low, providers may be incentivised to reduce the quality of their services, or seek to maximise the volume of supports delivered, to ensure they remain viable. These consequences are detrimental to both participants and the scheme.

The Review heard from many service providers and peak provider organisations that the sector is at a 'tipping point', with insufficient prices threatening the viability of providers to operate in the NDIS.

In its submission to the Review, the Ability Roundtable highlighted the financial stress experienced by service providers and provided analysis of data from "40 participating organisations representing around $5 billion in revenue, more than 35,700 workers and nearly 57,000 NDIS participants".[1860] The Ability Roundtable data suggests 68 per cent of participating organisations reported a loss in 2021-22 (with a median result of a 2.6 per cent loss), and 64 per cent of participating organisations reported a loss for the first six months of 2022-23 (with a median result of a 0.8 per cent profit).[1861] The Ability Roundtable also suggested "the 9% increase for disability support workers pricing, as part of the 2021-22 Annual Price Review (APR), helped to flatten the downward trend in financial performance for participating organisations" over the first six months of 2022-23.[1862]

> *"... despite the flattening of the downward trend in the 2022-23 FY, the pricing decisions taken by the NDIA Board have not been sufficient to ensure the ongoing viability of participating organisations over the long term ... assuming costs and other revenue don't fundamentally change, more than 76% of the group will operate at a loss [in 2023-24 FY]. For more than 50% of the group this would mean three years trading at a loss."* – The Ability Roundtable[1863]

Similarly, the StewartBrown *Disability Services Financial Benchmark Report* found 61 per cent of organisations reported an operating loss in 2021-22, a significant increase from the 47 per cent of

organisations that reported an operating loss in 2020-21.[1864] The StewartBrown report suggested "the average operating margin was a loss of 2.6% with the bottom quartile reporting an average operating loss of 12.6% and first quartile reporting an average operating profit of 5.8%".[1865]

> *"The operating loss is an unsustainable result and effects both the investment in the sector and the ongoing viability of a number of providers." – StewartBrown, Disability Services Financial Benchmark Report* [1866]

4.3.4   Price caps act more as a 'price anchor' than a 'price ceiling'

Setting an efficient or benchmark price itself can have sustainability benefits.

Getting the level of this 'efficient' price right is hard but it is vital for encouraging the right volume, nature and quality of supply.

A price level that is too low may not incentivise providers to join the scheme, which could prevent participants from having access to adequate supports.[1867] The National Disability Services *State of the Disability Sector Report 2022* found almost three out of five (59 per cent) of surveyed providers said they were worried they would not be able to provide NDIS services at current prices.[1868]

Conversely, a price level that is too high would put pressure on the total cost of the scheme.

Box 66: What is 'price bunching'?

Price bunching is where the amount charged for delivering supports is close to the price cap for the support.

If the price charged is within 95 per cent and 100 per cent of the price cap, then the claim is considered to be "at or close to" the price cap.

Unless stated otherwise, analysis of NDIS payments data to measure price bunching is based on payments made during 2022-23. It excludes some payments, such as:

- Supports being self-managed
- Supports that are not price controlled
- Supports that are not delivered as an hour of support – that is, a "unit serviced" support.

In the NDIS, most payments occur at the price cap. In 2022-23, of those payments subject to a price cap, 79 per cent were charged at exactly the price cap.[1869]

Box 67: Most NDIS payments are subject to price caps and, of those, most are charged at or close to the price cap

In 2022-23, **83 per cent** of payments were subject to a price cap.[1870]

Of those payments subject to a price cap:[1871]

- **82 per cent** of payments were charged between 95 and 100 per cent of the price cap
- **79 per cent** of payments were charged at exactly 100 per cent of the price cap.

There are reasonably high levels of price bunching across both core and capacity building supports, and supported independent living (SIL) and non-SIL participants. However, price bunching is particularly evident for capacity building supports. Of the payments made for capacity building supports in 2022-23, 90 per cent of payments by SIL participants, and 80 per cent of payments by non-SIL participants, were charged at or close to the price cap. [1872]

Figure 123: Rate of price bunching for SIL and non-SIL participants across core and capacity building supports, 2022-23[1873]
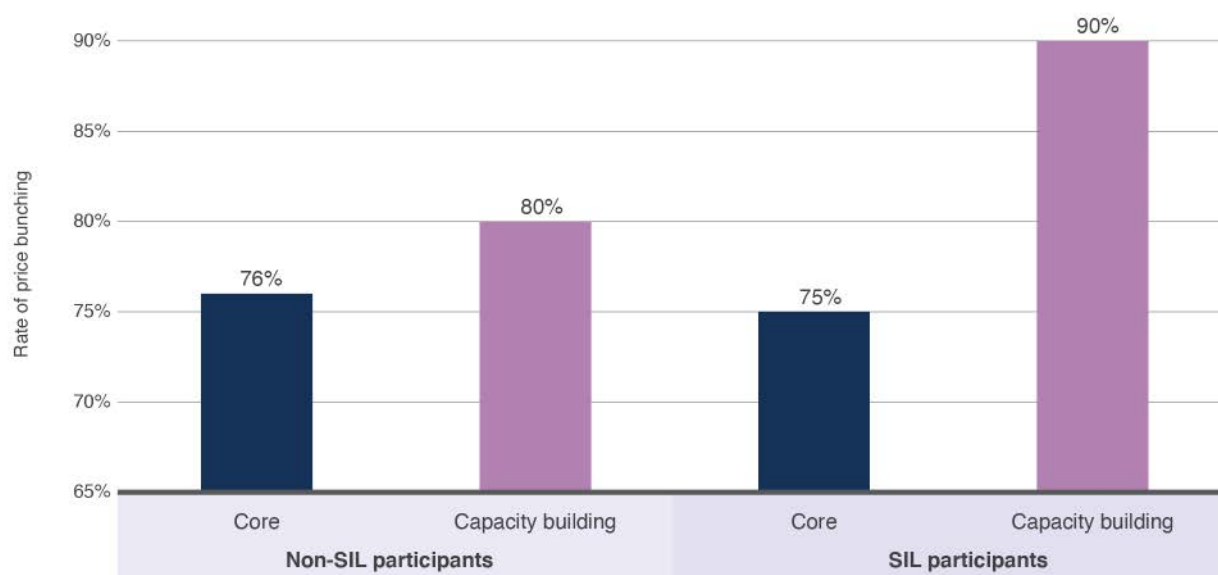
We know that providers often charge participants at the maximum price. In the NDIA's 2021-22 Financial Benchmarking Survey, over four in five providers (83 per cent) reported always setting prices at the price cap. A small share of providers (16 per cent) said that they 'sometimes' set prices below the price cap. The top reasons for setting prices below the price cap included: participants' budgets having limited funds and needing to be reviewed; and providers wanting to remain competitive.[1874]

We also heard from participants, families and carers that it is difficult to find supports that are below the price cap.

> *"NDIA staff have a misinformed perception that participants (especially those who self-manage) hold significant power to negotiate with providers in relation to fees*

charged. Providers simply refuse to provide service and move on to the next participant." – Carer[1875]

A lack of price responsiveness from participants may also be a contributing factor. There could be many reasons for this, including: participants having a preference for trust-based and long-term relationships with providers and workers; participants having limited confidence or support to find alternative providers; or high 'switching costs' (including time and effort) for participants when changing providers.

Participants may be slow to switch between providers when dissatisfied. In this case, market 'competition' will be less effective. Other mechanisms – including reliable, timely and effective information provision, effective navigation support, and proportionate safeguarding – is needed to ensure the delivery of safe and quality supports.

4.3.5 'Price gouging' and 'price differentiation'

We heard that participants being charged more than non-participants was not just confined to therapy supports, with some calling this 'price gouging'.

> *"Another problem is that providers are price gouging. As soon as they hear you're on NDIS they literally change the quoted amount."* – Participant[1876]

> *"Price gouging is rife … Everyone charges the maximum price, irrespective of quality of service, experience, flexibility."* – Carer[1877]

> *"Participants also advised that while they might have some control over the fees they pay providers for services, providers often expect to be paid 'top dollar' even when they're new and inexperienced."* – NDIS Quality and Safeguards Commission, Own Motion Inquiry into Platform Providers[1878]

'Price gouging', or setting excessively inflated prices, are not on their own illegal.[1879] However, under Australian competition laws, businesses must not engage in anti-competitive behaviour that misleads consumers about what they'll be charged or why, and must not collude with their competitors in setting prices.

It is important to note that not all instances of 'price differentiation' constitute 'price gouging'. For example, some general practitioners (GPs) regularly 'bulk bill' some patients (for example, those with a Health Care Card, or where a patient is receiving numerous treatments over a short period), while charging others more.

Similarly, there may be valid reasons why prices for some supports are higher for some participants.

> *"Many providers are now being blamed for "price gouging" or abusing the system. However these problems are largely created by the incentives at play … Of course, participants could in theory take control of their funding and negotiate a lower price to stretch their funding further than their planner budgeted for. But asking for a better*

deal is asking a provider to accept less than has been established as 'reasonable and necessary'." – Dr Simon Duffy and Dr Mark Brown, commissioned by Disability Advocacy Network Australia (DANA)[1880]

Providers may face additional regulatory and administrative costs when delivering services to NDIS participants. For example, while the range of audit costs vary according to provider size and scope, registered NDIS providers face a median cost of $935 for verification audits, which must be conducted every three years.[1881] Registered NDIS providers who deliver more complex supports face a median cost of around $3,000 for certification audits. These audits must be conducted every three years, with additional costs for mid-term certification at the 18-month mark.[1882] Additional indirect costs are also likely to be incurred by providers when preparing for these audits. These indirect costs can exceed the direct audit costs.

Price differences may reflect differences in participant complexity or delivery method and, in these cases, may be appropriate if they improve participant outcomes.

Price differences, however, are also likely to represent in part a lack of incentives for providers and participants to provide and seek supports below the price cap.

"My planner complained about the charge our physio charges us, but it is in line with NDIS price guidelines. When I explained this to my planner, she advised that was only a ceiling and no one should be charging that much. If you are going to put high prices in your price guidelines, you have to expect to be charged those prices." – Carer[1883]

"... when people tell stories of artificially high prices for services they may think that the provider is somehow to blame ... But the reality is that providers are trying to survive in a complex world and their chance of survival is largely based, not on their links to community, not on their relationships with people with disabilities, but on their ability to interpret and live by the funding rules set by the NDIA." – Dr Simon Duffy and Dr Mark Brown, commissioned by Disability Advocacy Network Australia (DANA)[1884]

In September 2023, the NDIS Commission published two short documents with guidance on price differentiation to help participants and providers "identify where sharp practices may be occurring and what action they can take in response". The documents articulate the NDIS Commission's expectations for providers, including that they "act with honesty, integrity, and transparency", including with regard to how they set prices for NDIS supports.[1885]

The guidance material notes "If a provider sets a different price for a product or service offered to NDIS scheme participants compared to others outside the scheme, the Commission expects providers to be able to justify it. If a price difference cannot be justified, it may be a breach of the Code of Conduct and considered a 'sharp practice' by the provider."[1886] The NDIS Commission noted it would also stand up a team to manage and respond to complaints about these issues.[1887]

Together, the associated actions under the proposed new pricing and payment framework aim to address current concerns around 'price gouging'. These actions include:

- Transitioning to a fully electronic payment system (see Action 10.3), which would capture more data on all NDIS transactions (including prices being charged) to inform data-driven pricing.
- Providers would have stronger requirements to disclose the prices they are charging for NDIS supports, including via the centralised online platform (see Action 10.1), and relevant financial information to inform how price caps are set (see Action 11.1).
- The Independent Health and Aged Care Pricing Authority (IHACPA) would be responsible for advising the Australian Government on the prices for NDIS supports (see Action 11.3) to improve transparency and to ensure greater alignment when setting prices across the care and support sector.
- A wider range of payment approaches would better reward providers for the value of supports being delivered rather than the volume (see Action 11.1).
- Preferred provider arrangements for capital supports (including assistive technology) would enable governments to better leverage their buying power and to get a better deal for participants (see Action 11.2).

4.3.6 Price caps can have unintended consequences

"The current pricing model used by the NDIS is flawed … This approach creates incentives for providers to cut costs rather than improve quality, leading to homogeneity rather than innovation and poorer outcomes for people with disabilities. In the long run, this approach is not only harmful to those who need high quality services, but also unsustainable for the NDIS itself." – Provider[1888]

When bluntly-applied and based on poor evidence, price caps can create unintended service gaps. This is especially so if they do not take into account differences in the 'market' price at which providers are willing to supply services, such as for participants with more complex needs.

Participants with complex needs

Providers have little incentive to compete on price or quality when price caps act as an 'anchor' and how they are set mostly does not adjust for quality or complexity. In this environment, providers have little to no incentive to charge below the price cap for lower quality supports and services.

Instead, the current price caps can lead to 'cream skimming', where providers only take on participants who present the 'highest profit margin'. In this way, price caps can create unintended service gaps where they do not take into account differences in the 'market' price at which providers are willing to supply services.

Figure 124: A stylised example of a single loading for complexity

A single loading for complexity...

...can lead to prices caps being below the cost of providing supports for participants with more complex needs

Cost

Complexity of needs

- - - Price offered by the NDIS ——— True cost of support (dependent on complexity)
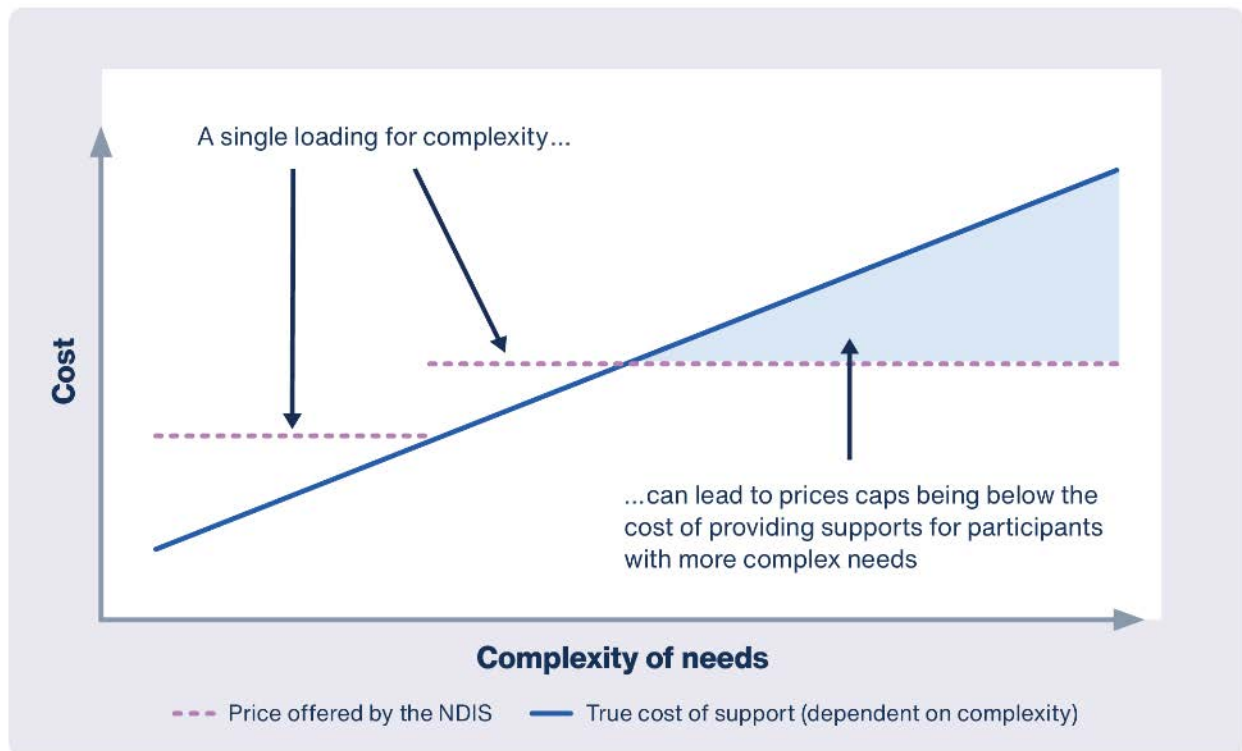
We have heard reports that some participants with complex needs are having difficulty accessing supports.

> *"Existing pricing models also create a system whereby providers may select participants who present high profit margins, and deny access for participants with more complex needs. As others have argued, this leads to the operation of Inverse Care Law within the NDIS, where the availability of services varies inversely with the need for it. Inverse Care Law is exacerbated when supports and services are exposed to market forces, as in the NDIS market-based model." – Women with Disabilities Australia[1889]*

Analysis of plan utilisation rates shows that participants who have a higher level of function – based on the NDIA's current assessment of functional capacity – have, on average, lower plan utilisation rates.

Figure 125: Plan utilisation rates by participant level of function as at 30 June 2023[1890]
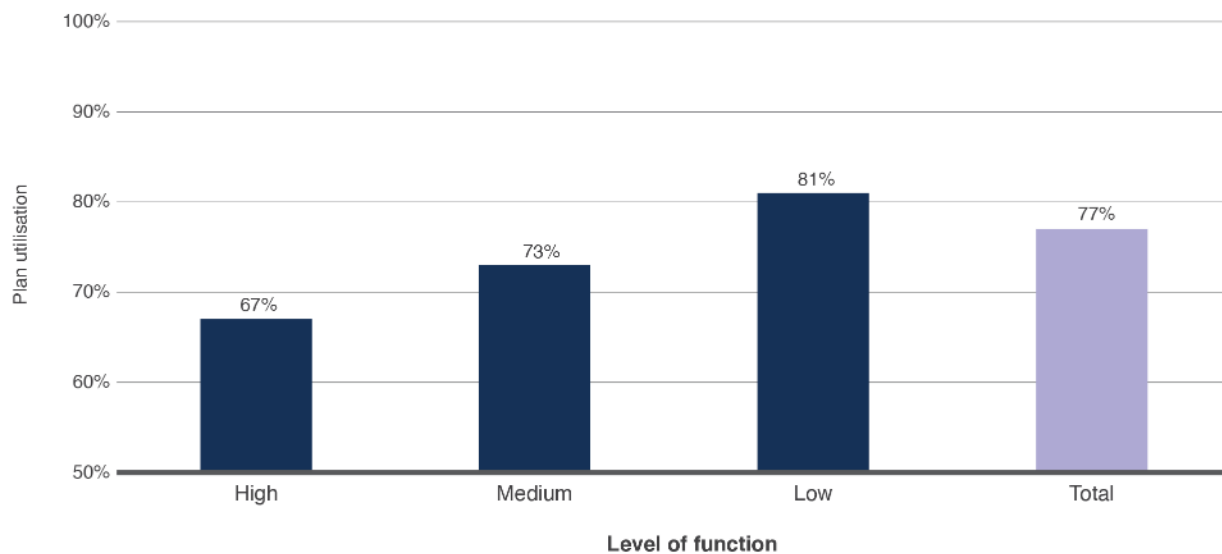
This trend is apparent even when excluding supported independent living (SIL) participants from the analysis. Between October 2022 and March 2023, non-SIL participants with the lowest level of function had the highest plan utilisation rate, while participants with the highest level of function had the lowest plan utilisation rate.[1891]

However, rates of price bunching tend to be higher for participants with a low level of function – and this is especially the case for capacity building supports. In 2022-23, the rate of price bunching for capacity building supports was 83 per cent for participants with a low level of function, compared with only 77 per cent for participants with a high level of function.[1892]

Figure 126: Price bunching rates in 2022-23 for Core and Capacity Building supports by participant level of function [1893]
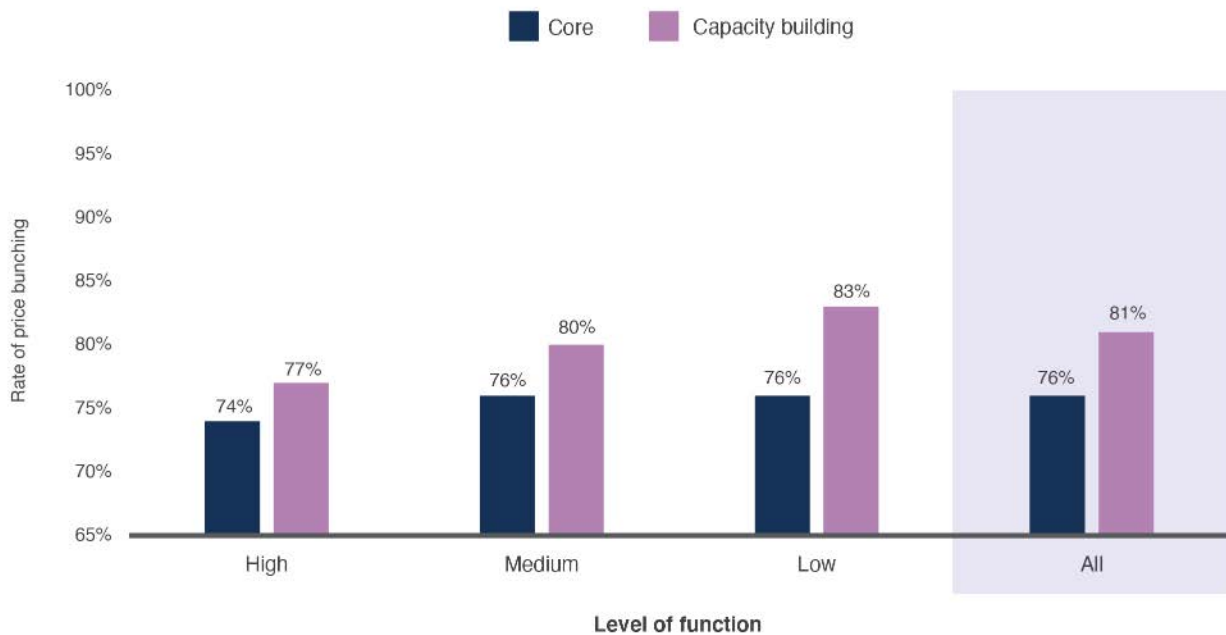
The Joint Standing Committee on the NDIS (NDIS JSC) Inquiry into Market Readiness also highlighted that the current pricing approach is not working for participants with more complex needs.

> *"The committee has heard on many occasions that the NDIS pricing framework is not working for participants with high and complex needs. ... Indeed, the committee has heard evidence that some service providers are 'cherry picking' clients and potentially leaving some of the most vulnerable NDIS participants with no access to adequate services." –NDIS JSC, Inquiry into Market Readiness[1894]*

We have heard that NDIS price caps should give greater consideration to the additional costs associated with delivering supports to participants with more complex needs.

> *"Pricing differentiation should also consider the complexity of participant need and the markets/sub-markets in which services are delivered." – Provider[1895]*

Any price differentiation should be data-informed and reflect the cost factors that are incurred by providers who deliver quality supports to participants with complex needs.

This could include considering the potential for increased worker compensation and insurance costs, higher personal leave rates and staff burnout, increased supervision levels and worker training/qualification requirements.

Any differentiated prices should be aligned with agreed definitions of complexity and the circumstances where these additional costs are required, to prevent 'gaming' from providers.

Participants living in different regions, including in rural areas

Some participants may have trouble accessing adequate supports in rural parts of Australia (MMM 3-5) when compared with participants who live in metropolitan areas (MMM 1) or regional centres (MMM 2) (see Section 5.4).

The Melbourne Disability Institute found in 2023 that 'participants who live in regional and remote areas receive slightly smaller plans' and 'participants who live in socio-economically disadvantaged areas on average received smaller plans', though 'inequalities were relatively small'. This analysis highlighted that those living in regional, rural and remote areas are more likely to be in a socio-economically disadvantaged area and that arguably those in regional, rural and remote areas require larger plans to receive equitable access to supports as those living in areas where services are more readily available.[1896]

Box 68: Defining remoteness: Modified Monash Model (MMM) Classification

There are different ways to classify locations by remoteness.

The scheme primarily uses the Modified Monash Model (MMM)[1897] to categorise locations in Australia according to their population and distance from capital cities. MMM classifications are based on the Australian Statistical Geography Standard – Remote Areas (ASGS-RA) framework used by the Australian Bureau of Statistics (ABS). There are 7 classifications:

- MMM 1 refers to **metropolitan areas**. These are major cities accounting for 70 per cent of Australia's population, and all areas are categorised as ASGS-RA1.
- MMM 2 refers to **regional centres**. These are inner (ASGS-RA 2) and outer regional (ASGS-RA 3) areas that are in, or within a 20km drive of a town with over 50,000 residents.
- MMM 3 refers to **large rural towns**. These are inner (ASGS-RA 2) and outer regional areas that are not MMM 2 and are in, or within a 15km drive of a town between 15,000 to 50,000 residents.
- MMM 4 refers to **medium rural towns**.These are inner (ASGS-RA 2) and outer regional areas that are not MMM 2 or MMM 3, and are in, or within a 10km drive of a town with between 5,000 to 15,000 residents.
- MMM 5 refers to **small rural towns**. These are all remaining inner (ASGS-RA 2) and outer regional (ASGS-RA 3) areas.
- MMM 6 refers to **remote communities**. These are remote mainland areas (ASGS-RA 4) AND remote islands less than 5kms offshore. Additionally, islands that have an MMM 5 classification with a population of less than 1,000 without bridges to the mainland will now be classified as MMM 6.
- MMM 7 refers to **very remote communities.** These are very remote areas (ASGS-RA 5), including all other remote island areas more than 5kms offshore.

There are fundamental differences in the cost of delivering supports to participants in rural areas when compared to metropolitan areas or regional centres. The current approach of having a single price cap across non-remote parts of Australia is administratively straightforward, but can create challenges for providers who offer supports in some of these areas.

A more granular look at rates of price bunching by state and MMM classification shows significant variation. The rate of price bunching differs at the same MMM classification, across different states and territories (Figure 127). This variation suggests there may be merit in considering supports prices and loadings by different regions. However, there is also a need to balance such differentiation with additional complexity in pricing arrangements.

Figure 127: Price bunching by remoteness and state and territory[1898]

Classification	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	Total
MMM 1	78%	80%	N/A	75%	67%	N/A	79%	80%	77%
MMM 2	33%	78%	84%	80%	63%	79%	84%	81%	80%
MMM 3	N/A	80%	N/A	79%	69%	86%	79%	79%	79%
MMM 4	N/A	79%	N/A	78%	73%	82%	79%	80%	79%
MMM 5	N/A	79%	80%	78%	66%	82%	80%	78%	78%

In remote (MMM 6) and very remote (MMM 7) areas, price cap loadings have been increased to support participants to have better access to services by recognising the additional cost for providers who deliver services in these areas. However, providers who deliver services in some regional and rural parts of Australia, particularly small rural towns (MMM 5) and medium rural towns (MMM 4), may face similar underlying geographic cost drivers as in remote areas.

> *"… further [price] differentiation to encourage growth in markets in regional and remote locations is required. This would incentivise increasing numbers of therapists to provide services to NDIS participants in these locations whilst also ensuring adequate remuneration of operating costs for those already doing so." – Allied health organisation[1899]*

As part of engaging with the Review, Ability First Australia recommended applying a price loading to NDIS supports delivered in MMM regions 3-5, to support the sustainability of services in these communities.[1900]

> *"It is difficult to sustain local services under the current pricing model as regional services are delivered at higher costs across smaller populations than in metropolitan areas. In spite of best efforts to create viable markets, while successful in some current regional and rural areas, some areas do not appear to have latent capacity to become viable… Pricing supplementation for NDIS services only applies to MMM regions 6 and 7, however costs are also higher in MMM regions 3-5 which attract the same rate as metropolitan areas." – Ability First Australia[1901]*

Differences in provider costs associated with offering supports in rural areas with lower population density should be considered when setting prices to improve participant access supports. Any such consideration for differences in provider costs should be balanced with avoiding unnecessary complexity in pricing arrangements.

Accounting for costs in more rural and remote parts of Australia would go some way to improving participants' access to safe and quality supports, but price settings alone may not be enough to overcome some of the current challenges with market coordination in these areas (see Section 5.4). Pricing and payment approaches alone are also not sufficient to deal with the diverse and unique challenges of delivering supports in remote and very remote communities (see Section 6.2).

Supports delivered in group settings

Current pricing arrangements may make it difficult for participants to access group-based supports, as the pricing arrangements may have disincentives for providers to deliver supports in group settings.

Prior to the NDIS, some people with disability could access block-funded group-based day programs, which offered a range of community, social and recreational activities in their community or in a centre. Not all people with disability could access these supports, and there was very little choice or control over what community, social and recreational activities were provided in group settings.

The NDIS aimed to increase choice and control through individualised funding arrangements. However, current NDIS pricing arrangements may provide perverse incentives to deliver supports that do not effectively build participants' connections and inclusion in their communities.

Under the transitional (i.e. 'original') pricing arrangements, which are effective until 31 December 2023, group-based support items had pre-defined support worker to participant ratios and incorporated a range of overhead costs (including capital costs for centre-based group supports). The rigidity of these pricing arrangements saw the introduction of new pricing arrangements for group-based activity supports in the 'Assistance with social, economic and community participation' support category.[1902]

According to the NDIA, these new pricing arrangements aim to offer providers and participants more flexibility to agree on and apportion non-face-to-face costs in a way that better reflects the cost of meeting the individual participant's needs in group-based settings, and can offer improved incentives for providers to deliver these supports to groups of participants.[1903]

We heard from providers that the new arrangements are administratively burdensome and costly. In part this could be due to the transitional arrangements, where both 'new' and 'transitional' (i.e. old) group support arrangements are available to providers.[1904] These transitional arrangements allow providers to transition groups of participants in stages, but once a group has moved to the new pricing arrangements, they cannot revert to the transitional (i.e. original) pricing for that particular group or centre-based support.[1905]

On the other hand, we also heard it can be challenging for participants, their nominees and Plan Managers to check invoices, since the hourly rate depends on the actual numbers attending each group activity and it is difficult – or impossible – to independently verify this.

Figure 128: Differences between the original and new pricing arrangements for group-based supports[1906]

	Original pricing arrangements	**New pricing arrangements**
Claiming for group supports	Relevant group support items are 'all inclusive' and claimed as a single 'line item', with worker costs associated with face-to-face work, non-face-to-face work and capital centre costs all included a single hourly price limit for each support item.	For relevant group support items, face-to-face work, non-face-to-face work and capital centre costs can be claimed as separate 'line items', giving providers flexibility around support ratios and how non-face-to-face time is apportioned per-participant in the group.
Worker-participant ratios	Large number of support items, with one item for each of the group sizes (i.e. worker-participant ratios). Possible group sizes are pre-defined via the support items in the NDIA's Pricing arrangements and price limits document. Each support item has a pre-defined worker-participant ratio (e.g. 1:3, 1:5), and lower price limits that reflect these rigidly-defined ratios, offering limited flexibility in participant group sizes when delivering these supports.	Small number of support items, and no pre-defined group sizes (i.e. worker-participant ratios). Provider can decide on group sizes. Providers claim a base hourly price that they can flexibly 'divide' as needed based on the number of participants attending. That is, for relevant supports the price limit for each participant is the applicable price divided by the number of participants in the group.
Non-face-to-face costs*	Hourly price limits 'bake in' a fixed amount for non-face-to-face time regardless of actual time spent. Time spent on non-face-to-face work is assumed to have been shared equally on the group's participants. Providers are not permitted to separately bill each participant for this time.	Provider costs associated with a group supports non-face-to-face time can be negotiated and claimed per participant based on actual costs (i.e. time spent). Providers can separately claim for time spent on non-face-to-face work.
Centre capital costs#	Hourly price limits also 'bake in' a fixed amount of $2.44 for centre capital costs.	Providers 'centre capital' costs for centre-based group supports can be claimed separately for each participant, on top of the 'base' hourly amount and 'non-face-to-face' components of the activity.

*Non-face-to-face costs may include pre- or post-face-to-face support work, such as time spent doing reasonable preparation that enables planned support activities to take place.

#Centre capital costs support providers in meeting the 'fixed' costs associated with delivering care in a facility.

But can't we just remove price caps?

Removing price caps could help to address unintended supply gaps and allow providers to compete on quality as well as price.

> *"Setting inappropriate price caps can affect access to supports and the sustainability of support provision, create uncertainty that can deter investment, and impede the development of new forms of supports." – Queensland Productivity Commission[1907]*

Indeed, there has been a long held view that prices should be deregulated once the NDIS market is mature.

> *"'Prices should only be regulated as narrowly and for as short a time as possible." – Productivity Commission[1908]*

The NDIA's 2019 Pricing Strategy lays out a four-step transition approach for pricing that is "aimed at maintaining and increasing market supply, assisting in the transition of the NDIS to full roll out and helping markets grow to a more mature state in the future, while recognising the need for financial sustainability" (Figure 129).[1909]

Figure 129: NDIA 2019 Pricing Strategy pricing transition approach

The NDIA's approach seeks to decrease the level of pricing intervention – moving from the current 'heavy handed' price setting and approval to more 'light touch' price monitoring and information provision.

However, this transition process has not progressed. Price monitoring and comparisons in the NDIA is limited due to cumbersome NDIS systems and the incomplete information captured on what is happening in markets, including the prices being paid (see Section 2.1*)*

A 'light touch' price monitoring approach, on its own, may not be sufficient

Past reviews have identified two common reforms. The first is for NDIS pricing arrangements to progressively move away from price caps and controls, and the second is to introduce a 'light touch' price monitoring approach (Figure 130).

Figure 130: Level of intervention by government on pricing

Decreasing level of intervention by government on pricing

Price setting and price approval		Price Monitoring	Price information
• Steward sets prices • May include setting limits on prices or the allowed rate of return or revenue • May also include setting prices relative to the observed market rate	• Providers are required to submit their prices to the regulator for approval • Similar to current quotation system for assistive technology • High compliance costs	• Steward monitors and reports on actual market transaction prices • Steward can require providers to disclose or publish information on prices	• Participants provided with price information to help with decision-making • Some discipline on provider pricing behaviour

Under current settings in the NDIS, removing price caps could place substantial pressure on scheme costs.

In social markets like the NDIS, participants are likely to be less responsive to prices than in private markets. Unlike when choosing everyday goods and services, price will often not be the main factor driving participant choice in supports and services. For some supports like personal care, choice is often driven by the person (or worker) who is delivering the support or service, and the trust in and the relationship with the person.[1910] We have also heard that participants are fearful that if they don't use their budget it will mean it is reduced in the future (see Chapter 2). A culture of mistrust and lack of certainty about future funding can reduce incentives to search for the 'best price' for supports.

With plans being complex and confusing and participants not being sufficiently supported to understand or use their plans (see Chapter 2), participants may also rely on providers for advice on what supports or services are needed, and how much they cost. Without sufficient competitive pressures in the scheme, providers can 'bid up' the price of supports and removing price caps risks a potential 'ratcheting effect'. When NDIS budget-setting processes depend on the price of services, there are pressures for budgets to rise to meet prices rather than the reverse.

"The bureaucracy of NDIS and its outrageous and free-wheeling price guide increases have allowed service providers to charge optimal rates without any obligation to adjusting their support services to the needs of their clients. NDIS has become a business model for service providers to take advantage of the never-ending funding from client, without having to answer for whether or not they are improving services to the benefit of the participant." – Carer[1911]

Providers may also induce or increase demand for their supports (see Section 4.2.1). Without price caps, providers would face even greater financial incentives to deliver more supports, regardless of outcomes or benefits to participants, than they do currently. As supports become more profitable for providers, price deregulation could also have a 'volume ratcheting effect' where there is enough space or flexibility in participant budgets.

So although important, improved price monitoring and transparency alone would not be sufficient to address the lack of competition on price and quality across NDIS markets. Instead, removing price caps would likely to lead to increased costs without an associated improvement to outcomes for participants, placing pressure on scheme sustainability.

For now, price caps and other price controls provide an important constraint on how much participants are charged in current NDIS markets. The focus should instead be on underpinning market reforms that help support NDIS markets to function well, including better aligning incentives for participants, providers and governments.

4.4. There is a lack of transparency, predictability and confidence in current the NDIS price-setting process

A lack of independent advice and evidence around pricing decisions has added to uncertainty for providers, and can potentially discourage investment in the sector. For example, prices for some supports have been frozen over recent years – including prices for therapy supports, which have been frozen since 2019-20.

4.4.1 Opaque price setting processes is eroding confidence in NDIS pricing and payment approaches

The NDIA has been criticised by service providers and practitioners for not considering, or not explaining how it has considered, evidence and data provided through Annual Pricing Review consultation processes.

"It is clear that the current approach does not collect sufficient data, does not compare comparative data accurately, discounts data provided by stakeholders, and doesn't make decisions that are consistent with broader market and economic trends, or does not apply these consistently." – Occupational Therapy Australia[1912]

Advocates and disability representative and carer organisations have also suggested that the consultation process for Annual Pricing Reviews does not sufficiently hear from participants and their representatives.

"The annual price review typically includes consultation, for example through a consultation paper. However, the consultation appears to occur primarily with industry interests. In the last price review, only 12 out of 304 submissions came from participants and their representatives." – Advocate[1913]

While the NDIA established a Pricing Arrangement Reference Group to provide advice to the NDIA Board,[1914] this alone has not been sufficient to deliver transparency and certainty for providers. This is especially so given the group is chaired by an NDIA staff member, relies on internal NDIA analysis, and provides its advice to the NDIA Board through the NDIA CEO.

"Independence, transparency, fairness, enhanced consumer engagement and accountability as best practice governance requirements for price regulators. The NDIS, by contrast, currently lacks independent price regulation. There are concerns among stakeholders with respect to price transparency and fairness." – National Disability Services[1915]

"Uncertainty is further compounded ... by the lack of evidence and independence in the price setting approach. Currently, the use of limited data and price caps that for the main part are based on an estimate of the cost-of-service provision for the lowest cost providers, does not necessarily reflect average or true operating costs providers experience in their day-to-day operations." – Provider[1916]

Historically, the NDIS Commission, which has responsibilities for both quality and safeguards, has had limited input into the NDIA's price-setting process. This is unbalanced.

The Productivity Commission, in its 2017 Review of NDIS Costs, recommended that the NDIS Commission should monitor and, in the longer term, set prices for NDIS supports. This approach was resisted by the NDIA, and the Australian Government decided that the NDIA should continue to set prices. This was on the grounds that the NDIA could continue to prioritise sustainability when setting prices. However, this can introduce other issues, which are discussed below.

4.4.2   Greater independence in the NDIS price setting process

Setting prices for NDIS supports is complex. Price setting needs to balance many objectives including promoting cost efficiency, stimulating innovation, encouraging the supply of quality supports, maintaining and building safeguards, and ensuring scheme sustainability.

In 2017, the Productivity Commission noted its concern that while "... the price-setting mechanism is held within the NDIA, there is an incentive for it to be used to offset budget pressures".[1917] The Productivity Commission also emphasised the need for prices to be set with market development as the primary focus.

The incentives for the NDIA to use price setting and budget setting to manage the scheme's financial sustainability pressures is high. The NDIA has a number of roles; it is the funding body; it holds the price-setting mechanisms; and the NDIA Board and Scheme Actuary holds primary responsibility over ensuring scheme sustainability.[1918] However, it is apparent that the NDIA's

approach to setting prices has had a short-term cost control focus, when sustainability is a long-term concept which includes benefits and outcomes as well as costs.

Transition from the trial phase of the scheme also saw the significant and rapid increase in demand for disability supports which vastly exceeded supply, creating inflationary and quality pressures in the market.

The Productivity Commission recommended independent price monitoring and price regulation of NDIS supports, and for this to be administered by a government body or agency with relevant capabilities and necessary resources. [1919]

> *"There is a compelling case to legislate for an independent health price regulator that can set price caps independently, transparently and in an evidence-based manner. This will give providers and the community greater certainty (and participants certainty that they will receive the services that they need), and in turn, encourage new and existing providers to supply disability supports." – Productivity Commission*[1920]

Several submissions to the Review called for independent pricing in the NDIS.

> *"The NDIA Board has a dual responsibility for both setting NDIS pricing and Scheme sustainability. This can be a potential conflict of interest when market conditions, supported by data and insights, don't match the expected funding envelope provided by Government. The potential for a rationed approach to funding to manage sustainability is an ongoing and systemic point of frustration in the NDIS market ... The Ability Roundtable data supports the need for an NDIS Independent Pricing body responsible for the review and redesign of the NDIA's Cost Model to ensure the ongoing viability of the NDIS market, with an immediate focus on the appropriate application of efficient pricing principles (e.g. such as for operating expenses/overheads)." – The Ability Roundtable*[1921]

> *"The future price setting decision maker for the NDIS should be an independent body that is established separately to the NDIA, with clear terms of reference guided by a comprehensive analysis of the current and projected market, workforce demand and shortages, and other economic factors including inflation/CPI and increases in award wages. The independent price setting body should: undertake a comprehensive market survey to inform accurate and comparable pricing for NDIS services; and engage people with knowledge of the types of NDIS services provided, and who understand and can consider the complexity of different types of services, scope of role, and challenges that staff experience on the job." – Allied Health Professions Australia*[1922]

> *"There is no doubt that key to addressing the funding/payments system is transparent and independent pricing." – Alliance20*[1923]

> *"OTA strongly supports the adoption of an independent and transparent price setting body and process for the NDIS. The current price setting mechanism, which is an*

annual review undertaken by the NDIA, is perceived as being a fast and incomplete review mechanism that does not fully utilise stakeholder feedback or undertake a full analysis of the factors that are currently influencing the NDIS market and delivery of NDIS services. There is also a perception that NDIA's Annual Pricing Review is impacted by overall NDIA budget constraints in its final decision making. While budgetary impacts must be a key consideration, it should be transparently accounted for as an element of overall decision making, which does not occur currently"
– Occupational Therapy Australia[1924]

"Prices set by an independent pricing authority underpinned by best practice pricing approaches and drawing on existing data and experience in like systems will send appropriate signals to facilitate investment in workforce, outcomes and innovation."
– National Disability Services[1925]

The pricing approach used in the NDIS contrasts with pricing arrangements in aged care. Since July 2023, the Independent Health and Aged Care Pricing Authority (IHACPA) has provided independent advice to the Australian Government on pricing for residential aged care, residential respite care and in-home care. [1926] IHACPA uses evidence obtained through data analysis and stakeholder engagement to make recommendations on aged care pricing.[1927]

The Minister for Health and Aged Care is responsible for determining the prices for aged care services, based on IHACPA's advice, and the Australian Government and Department of Health and Aged Care "continue to be the system operators and responsible for the funding of aged care and aged care policy".[1928]

We have recommended that IHACPA should be responsible for advising the Australian Government on price caps for NDIS supports (see Action 11.3).

It is worth noting that in 2017, at the time of the Productivity Commission's Review of NDIS Costs, IHACPA was known as the Independent Hospital Pricing Authority (IHPA) and was only responsible for hospital pricing. Now that IHACPA is responsible for advising on aged care pricing, it is logical that it should be the body responsible for advising on NDIS pricing, given IHACPA's experience and expertise.

In providing advice on prices, IHACPA should consult with the Department of Social Services, the NDIA, the new National Disability Supports Quality and Safeguards Commission, state and territory governments, and the broader sector.

4.4.3 Price caps are not well aligned across the care and support sector

Price caps are used in the broader care and support sector, including in the Australian Government funded aged care and veterans' care sectors.

However, there is no coordinated approach to setting prices across these sectors, and prices vary across programs. These differences can create a situation where the Australian Government is effectively 'competing' with itself on prices across the care and support sector.

There could be benefit in more closely aligning prices across the care and support sector, drawing on government buying power. This could support scheme sustainability, the more efficient use of government funding, and ensure providers and workers are not deterred from offering services in different sectors, on the basis of different pricing.

> *"Government programs are, in effect, competing with each other to secure services for their target cohorts. For example, the policy and program settings for the NDIS and aged care, especially the pricing of services, put pressure on the market for veterans' services. The unintended consequence of this misaligned pricing can be underservicing of the veteran population. Therefore, market stewardship strategies for care and support services need to consider the flow on effects to other sectors which will require enhanced coordination across government departments." – Care and Support Economy Taskforce[1929]*

Expanding the remit of IHACPA to include providing advice on prices for NDIS supports (see Action 11.3) would enable greater harmonisation across the care and support sector. In turn, this could reduce 'distortions' between the delivery of aged care and NDIS services and ensure the Australian Government makes better use of its buying power across sectors.

4.4.4   Pricing social services and supports requires the necessary skills and expertise

Providing advice on prices for NDIS supports – or prices for other social services – requires expertise and specialist skills.

IHACPA is well positioned to advise on the prices for NDIS supports as it has experience determining acute hospital care prices over the past 12 years, and more recent experience with advising on aged care prices. IHACPA also has experience in pricing refundable accommodation deposits (RAD) in residential aged care.[1930] This knowledge and experience will need to be built on and may need supplementing by IHACPA when advising on pricing and costing matters for Specialist Disability Accommodation (SDA) (see Action 9.5).

IHACPA has recently developed 'pricing principles' for residential aged care, as part of its commitment to transparency and accountability in its decisions. The residential aged care pricing principles include 'overarching', 'process' and 'system design' principles (Figure 131) and are used "to inform decision making where IHACPA is required to exercise policy judgement in undertaking its functions relating to residential aged care costing and pricing."[1931] Many of these pricing principles would be strongly applicable in an NDIS context.

In addition, IHACPA has experience in conducting costing studies and developing normative models to determine prices that are informed by data and evidence. Further, it has established pricing consultation processes that are transparent and builds confidence in its approach to pricing.

Figure 131: IHACPA's residential aged care pricing principles[1932]

Overarching principles that articulate the policy intent behind the introduction of funding reform for aged care services:	• **Access to care**: Funding should support timely and equitable access to appropriate aged care services, for all those who require them. • **Quality care**: Care should meet the Aged Care Quality Standards, reflect continuous improvement, support resident wellbeing and deliver outcomes that align with community expectations. • **Fairness**: Activity based funding (ABF) payments should be fair and equitable, based on resident needs, promote the provision of appropriate care to residents with differing needs, and recognise legitimate and unavoidable cost variations associated with this care. Equivalent services should otherwise attract the same price across different provider types. • **Efficiency**: ABF should ensure the sustainability of the aged care system over time and optimise the value of the public investment in aged care. • **Maintaining agreed roles and responsibilities**: ABF design should recognise the complementary responsibilities of each government agency and department in the funding and management of aged care services, as well as providers in delivering aged care services.
Process principles that guide the implementation of activity based funding and any fixed funding arrangements:	• **Administrative efficiency**: Funding arrangements should promote effective and efficient processes and should not unduly increase the administrative burden on aged care providers. • **Stability**: The payment relativities for ABF should be consistent over time. • **Evidence based**: Funding should be based on best available information. • **Transparency:** All steps in the development of advice for ABF and fixed funding should be clear and transparent.
System Design principles that articulate the detailed elements of activity based funding design:	• **Fostering care innovation**: Pricing of aged care services should respond in a timely way to the introduction of evidence-based, effective new technology and innovations in the models of care that improve resident outcomes and service efficiency. • **Promoting value**: Pricing should support innovative practices and systems that deliver efficient, person-centred care. • **Promoting harmonisation**: Pricing should facilitate best practice, person-centred provision of care in the appropriate setting. • **Minimising undesirable and inadvertent consequences**: Pricing should minimise susceptibility to gaming, inappropriate rewards and perverse incentives. • **Using ABF where practicable and appropriate**: ABF should be used for funding aged care services wherever practicable and compatible with delivering value in both outcomes and cost. • **Person-centred**: Pricing adjustments should be, as far as is practicable, based on characteristics related to people receiving care, rather than those of providers

Rather than having to establish a new independent body and build the necessary skills and expertise to cost and price NDIS supports, the scheme should instead leverage the existing skills, expertise and experience of IHACPA. Expanding the remit of IHACPA should lean on its existing capability in pricing in similar supports and services, as well its processes to do so transparently and to enable greater harmonisation across the care and support sector.

4.5. Governments also need to better leverage their buying power to drive better prices and value for participants

Designing appropriate pricing and payment approaches which are tailored to the needs and characteristics of participants, providers and nature of supports are one way for governments to drive better prices and value for participants. However, governments should also better leverage their 'buying power' to deliver better value for participants.

4.5.1 The NDIS does not take advantage of its buying power to get a good price

Even in well-established markets, the NDIS does not take advantage of its 'buying power' to get a good price.

Price caps for therapy supports are informed by prices in the large and well-established private market for therapy services. The NDIA sets price caps for therapy supports with reference to available information on the top 75th percentile of private market prices.

As part of the 2021-22 Annual Pricing Review, the NDIA collected some data on the advertised rates of therapy supports delivered in the private market. This suggested the average hourly cost of therapy supports was $172 in the private market, compared with the NDIS price limit of $194 per hour for most therapy supports.[1933]

The scheme is a reasonably large purchaser of therapy supports in what is a well-established market. In 2022-23, over 600,000 participants (98 per cent) had funding for therapy supports in their plans.[1934] In 2022-23, agency- and plan-managed participants spent over $3.3 billion on therapy supports, and nearly three in four (74 per cent) therapy sessions delivered to agency- and plan-managed participants were charged at or close to the price cap.[1935]

Despite this, participants and disability representative and carer organisations report that participants often pay more for therapy supports than non-NDIS participants.

> *"When we go to therapies we pay the maximum price of the pricing arrangements when I could go in under my private health and not pay anywhere near the same costs." – Participant[1936]*

> *"I try to use mainstream services and products rather than go to disability specific market due to the ridiculous prices charged by providers. As has been stated time and again, an able bodied person can go to an allied health professional and be charged $90, but I go for the same service and because I am NDIS funded I get charged more*

than $200 ... Not only is it discriminatory but also costs the government more dollars, and the person with disability gets less support." –Participant[1937]

"Because the NDIS Pricing Arrangements and Price Limits covering particular therapy supports far exceed the fees charged by these providers to non-Participants, there is an inherent incentive for these providers to charge more than they might otherwise if the NDIS will write the cheque." – Disability representative and carer organisation[1938]

Re-thinking how participants and providers are incentivised through scheme settings will be critical in designing long-term price settings. Pricing and payment approaches are only one aspect of market design available to governments. Governments should also consider changing settings around market access – that is, approaches around who can deliver supports and the additional requirements or standards they need to meet around how supports are delivered. This could help improve participant access to quality and safe supports, particularly in rural and remote Australia.

Using different market access settings could be a more effective way to improve access to certain NDIS supports in some locations compared to price cap arrangements. For example, provider panel arrangements could leverage governments' buying power by setting up a group (or 'panel') of providers which participants have guaranteed access, and can choose from. These providers would need to agree to deliver services at an agreed price and/or standard to access NDIS markets in specified locations.

Rolling out provider panel arrangements for allied health supports in small and medium rural towns or other areas where participants face persistent supply gaps, would help ensure participants can access these supports regardless of where they live (see Action 13.2).

4.5.2 Exploring better ways to purchase assistive technology

In the NDIS, assistive technology is considered to be equipment or devices that help participants do things they otherwise couldn't because of their disability, or do something more easily or safely. This can include small items such as non-slip mats and special knives and forks, or larger items such as wheelchairs and powered adjustable beds. Assistive technology is meant to improve participants' quality of life and/or reduce participants' needs for other supports over time.[1939]

How participants are currently able to purchase assistive technology depends on the cost and risk of the particular item. Figure 132 shows the NDIA's guidelines on understanding assistive technology evidence, advice, assessments and quotes.

Figure 132: NDIA guidelines on understanding assistive technology evidence, advice, assessments and quotes[1940]

	Low cost assistive technology	Mid cost assistive technology	High cost assistive technology
What is the cost per item?	Under $1,500	$1,500 - $15,000	Over $15,000
What do I need to get funding in my plan?	You don't need written evidence. You can tell us what you need.	Written evidence from an assistive technology advisor.	Assessment from an assistive technology assessor.
What do I need to do before I buy the item?	Low risk - we suggest you get advice from an assistive technology advisor. Higher risk - you need written advice from an assistive technology advisor.	Written advice from an assistive technology advisor.	Assessment from an assistive technology assessor.
Do I need a quote?	No	No	Yes
Where is the funding in my plan?	Core budget	Capital budget	Capital budget

In some cases, participants need to talk to an assistive technology advisor to help identify the most appropriate assistive technology solution. This can include allied health professionals (for example, occupational therapists, physiotherapists, podiatrists, or speech pathologists), continence nurses, rehabilitation engineers, orientation and mobility specialists, assistive technology mentors (who have a recognised qualification in assistive technology advice), or other qualified practitioners.[1941]

To purchase high cost assistive technology (valued over $15,000), participants must get a quote and an assessment from an assistive technology assessor. To purchase mid cost assistive technology (valued between $1,500 and $15,000), participants do not require a quote, but must get written advice from an assistive technology advisor. However, to purchase low cost assistive technology (valued less than $1,500) participants do not require a quote and only require written advice from an assistive technology advisor if the support is considered 'higher risk'.[1942]

This approach provides a considerable amount of flexibility for participants when purchasing low cost assistive technology. This is because there are no price caps, quoting requirements or other 'price controls' for individual low cost assistive technology items, other than the upper $1,500 'boundary' before an item is considered mid cost assistive technology.

However, this means participants face a greater risk of providers charging them a higher amount than necessary when making these purchases, as providers are more likely to 'get away with' over-charging given the NDIA has little to no oversight of the purchase.

We heard from people who said they experienced situations where providers had charged them more for assistive technology than they would expect to pay outside the NDIS.

> *"I got an able-bodied friend to check the supplier of the shower chair for the price for the same model quoted as $500 for me through NDIS. He was asked if it was going to be purchased through NDIS, and he advised it wasn't. It was $200." – Participant[1943]*

> *"Too many people see it as easy money, at the expense of the disabled community. Legislating to prevent companies charging a private individual $2,000 for a wheelchair and the NDIS $8,000 for the same product." – Carer[1944]*

> *"…many participants are required to pay more for supports, assistive technology and services than non-NDIS participants seeking those same supports and services. Pressure to purchase disability-specific supports creates a system whereby providers can increase costs for the same service or product, effectively charging for the 'disability-specific' or 'NDIS approved' label." – Women with Disabilities Australia[1945]*

As shown in Figure 133, we see a spike in transactions at the $1,500 threshold. Between July 2020 and June 2023, 62 per cent more transactions were made just below the threshold – that is, between $1,401 and $1,500 – compared with transactions made between $1,301 and $1,400.[1946]

Figure 133: Low cost assistive technology payments (in the range of $900 to $1,700) made between July 2020 and June 2023[1947]
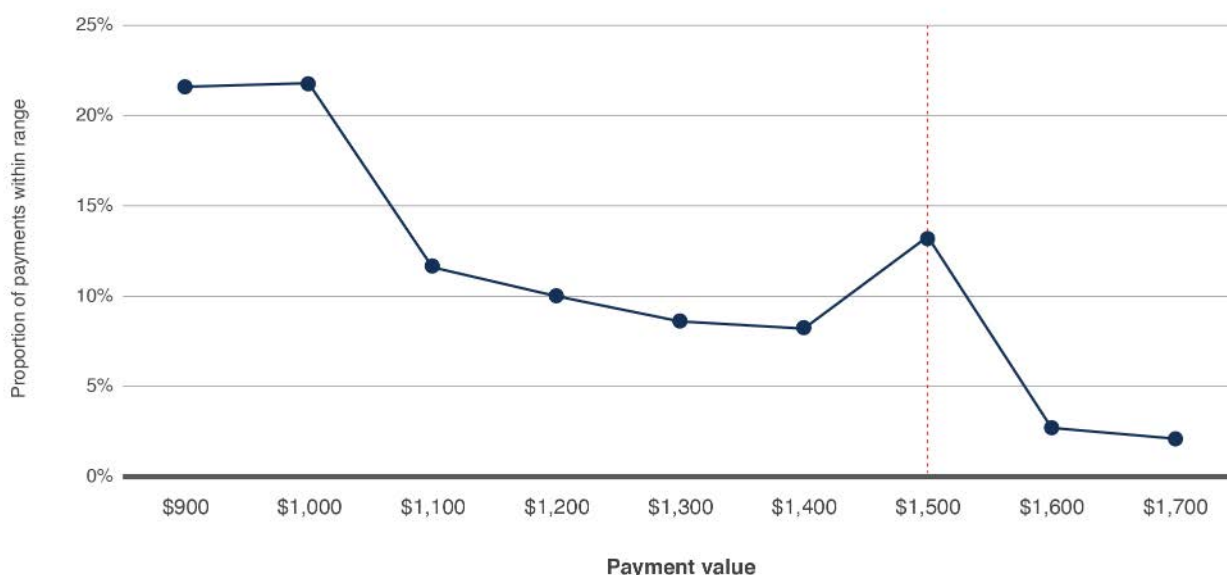
This suggests some providers may be charging participants the maximum amount they can without participants being required to get a quote. We have also heard that this might also be happening for some mid-cost assistive technology.[1948]

In 2022-23, NDIS participants spent $1.01 billion on capital supports (2.9 per cent of total payments), including $657 million on assistive technology (1.9 per cent of total payments).[1949]

There may be opportunities to increase the use of evidence-based assistive technology in the scheme, which could help reduce reliance on (or improve the value of) person-to-person supports. For example, investing in assistive technology could help participants to move around the home and in their community with more independence, which would improve outcomes for participants and reduce reliance on ongoing help from support workers. This would also reduce growing pressures on the workforce (see Recommendation 15).

We heard that there is a need to improve the delivery of aids and equipment outside the NDIS (see Chapter 1). We have also heard that there are opportunities to make greater use of assistive technology in the scheme.

> *"Assistive technology should not be seen as an expense, it's an investment. It can be the difference between doing a task independently or needing a support worker or family member to help. If there's one aspect of NDIS that really can be value for money it's AT (as long as the cheapest quotes are obtained, and the technology is suitable etc)." – Participant[1950]*

> *"The scheme is failing to operate like an insurance scheme because it is not minimising whole of life scheme costs due to a massive under-investment in 3 key areas: 1) assistive technology to reduce expensive and recurrent labour support costs, 2) innovative new models of care to reduce expensive and recurrent labour support costs, 3) big data analysis to identify outliers to inform efforts to minimise waste and corruption and highlight exemplars that can be copied and replicated to maximise scheme efficiency and enhance participant outcomes ... Massive under-investment in assistive technology, innovative new care models and big data analysis means the scheme is not evolving as quickly as it could. This results in a massive misallocation of resources, poorer participant outcomes, significantly higher levels of inefficiency and waste..." – Participant and provider[1951]*

Better coordination and information on what assistive technology is available and where to get it is needed both for people in and outside the scheme. This could be improved by a more nationally consistent approach for delivery of aids and equipment outside the NDIS (see Action 1.10). Better support to navigate the scheme (see Recommendation 4) would also provide participants with more independent advice and information on the range of assistive technology and other capital supports available, and what could work best for them.

The NDIS could better leverage its buying power to negotiate prices with providers of assistive technology and other capital supports. This would provide a simplified way for participants to access these supports, without limiting choice.

'Preferred provider' lists for assistive technology, home modifications and consumables should be progressively rolled out by the NDIA.

To set up these arrangements, the NDIA should negotiate with providers about how much these supports cost and the services the providers would deliver to better leverage government buying power and ensure participants get a better deal for these supports (see Action 11.2).

Preferred provider arrangements should also include published, user-friendly, and standardised service agreements covering repairs, maintenance and servicing (where relevant), as well as loan arrangements for assistive technology required for short periods. Preferred provider arrangements could also include guarantees about affordable and timely supply, for example, specified 'shipping rates' for different areas.

Participants should be allowed to purchase supports from other providers who are not part of a preferred provider arrangement, using a quoting approach. This would involve seeking and providing a quote to the NDIA. However, the NDIA must ensure this quoting process does not lead to lengthy backlogs in accepting quotes, which could result in participants being left without the supports they need. Participants should also be encouraged to purchase relevant supports from preferred providers where they are available and meet their needs.

Box 69: What preferred provider lists could look like for participants

Participants who are looking to purchase assistive technology (AT), home modifications and consumable supports should be able to purchase from a provider on the preferred provider list or other providers. Where needed, the participant's Navigator should help participants to seek independent information and advice on what AT or home modifications would best suit their needs, and to choose a provider.

If a participant chooses a preferred provider, then:

- As long as participants have sufficient funding, the participant should be able to purchase AT, home modifications and consumable supports without using a quoting approach. For higher cost, higher risk, more complex AT or home modifications, participants may still wish to seek quotes from the preferred provider to understand and compare different assistive technology or home modification solutions, but they should not have to provide to the NDIA. Participants should be able to get a better deal for the support(s) through the preferred provider.
- Where relevant and needed, the participant should be able to access repairs and maintenance of purchased AT or home modifications as agreed as part of the preferred provider arrangements. This could include access to loan arrangements for access to AT

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for short periods of time, for example, when there are repairs or maintenance being undertaken to AT or home modifications.

If the participant chooses to use another provider (who is not on the preferred provider list) then:

- The participant would need to seek and provide a quote from the provider to purchase AT, home modifications and consumable supports. Where the participant has sufficient funding in their budget – and quotes are in line with the price, quality and consumer protections of preferred provider arrangements – quotes should be accepted by the NDIA.
- The participant should still be able to access repairs and maintenance of any purchased AT or installed home modifications. These arrangements would depend on their service agreement with the service provider. Loan arrangements may or may not be included as part of this.
- In situations where there is limited or no availability of preferred providers, the participant should not need to use a quoting approach when the item is below a defined threshold. For example, participants should be able to purchase low-cost AT and low-cost, minor home modifications without a quote if the support is below a defined threshold per item. Participants should also be able to purchase consumable supports without using a quoting approach up to a defined threshold per year, noting these items are used more frequently.

Thresholds for purchasing consumables, low-cost assistive technology and low-cost, minor home modifications should be lower than the current threshold of $1,500 for low cost assistive technology. This is to ensure participants get a good deal when purchasing these supports, are less likely to face 'price gouging' from providers, and are covered by standardised service agreements that include maintenance and servicing, where relevant.

The thresholds should also incentivise quality providers to join the preferred provider arrangements. Without thresholds, there could be disincentives for providers to join the preferred provider arrangements and instead they may opt out of the arrangements so they can charge participants higher prices.

Other providers should be able to join the preferred provider arrangement at any time, if they are willing to provide supports at the negotiated or lower price, with the same or higher service quality. This would help ensure preferred providers remain responsive to participants.

The NDIA should consider opportunities to work with other government agencies to further increase buying power across government-funded programs.

There are a few examples of preferred provider arrangements being explored in the NDIS. For example, the NDIA has established a 'continence provider list' to help participants, carers and families "find trusted information on continence products and providers more easily". Continence providers are required to meet specific service requirements to be included on the list.[1952]

In May 2023, the Australian Government announced $29.3 million to work with participants and providers to make it easier to access quality assistive technology and other supports.[1953] DSS has said it will work with participants, service providers, advocates, peaks and leading researchers to "co-design": [1954]

- an expert advisory panel that will "assess assistive technology and other supports that have proven benefits and cost effectiveness, to make it easier for participants to find and access high quality evidence based supports that suit their needs"
- preferred provider lists for assistive technology products and other supports that will "assist participants to access high quality assistive technology supports at better prices, leveraging the buying power of the NDIS", while ensuring participants "continue to have control over where they source their supports and can choose to purchase from other providers outside of the lists".

4.6. A new pricing and payments framework is needed

A new NDIS pricing and payments framework is needed to help align incentives for participants, providers and governments. This should be developed by DSS and administered by the NDIA and IHACPA.

IHACPA should be responsible for advising on suitable indicators of the market price and price caps for relevant NDIS supports. IHACPA should consult with DSS, the NDIA, the National Disability Supports Quality and Safeguards Commission, state and territory governments, and the broader sector when advising the Australian Government on prices. Expanding the remit of IHACPA to include NDIS pricing would support greater alignment across the care and support sector and ensure government does not compete with itself and makes better use of its buying power across sectors.

The process for setting price caps should be transparent, and balance promoting the supply of quality and safe supports, innovation, provider viability and scheme sustainability. Providers should be required (with appropriate exemptions for smaller and enrolled-only providers) to disclose relevant financial information to inform NDIS price caps. This would include accurate, -up to-date information on the prices they charge for NDIS supports. The new NDIS pricing and payments framework should ensure that price caps:

- reflect the 'efficient market price' for delivering supports, including factoring in any costs associated with regulation (see Recommendation 17)
- use a data-driven approach to inform any price differentiation, such as to account for the costs of delivering supports to participants with more complex needs, in different geographic regions and in group-based settings
- should be guided by clear and transparent policy principles that are dynamic and reflect governments' priorities.

The new NDIS pricing and payments framework should also look at better ways to pay providers to promote the delivery of efficient and quality supports and continuity of supply. The framework should consider to what extent an efficent price should be set to a mean or median of benchmark provider costs. A range of payment approaches should also be explored to reward providers for the value of the supports delivered rather than the volume. This should include:

- where suitable, activity-based payments (for a defined group of services or 'activity') as well as other payment approaches.
- enrolment payments, which in time could include an outcome-based payment, for shared living supports (see Action 9.2).
- designing, testing and evaluating outcome-based payments for suitable supports to strengthen incentives for providers to deliver outcomes for participants. This should commence with rolling out an approach to measure and publish metrics of registered provider performance (see Action 12.3).

Fee-for-service payment approaches may still be a suitable way to pay for supports or services. However, governments should also consider opportunities to work with other government agencies to further increase buying power across government-funded programs. This should start with rolling out preferred provider arrangements for capital supports.

The development of new pricing and payment approaches should be informed by an initial costing study undertaken by IHACPA (see Action 11.3). An ongoing monitoring and evaluation framework

should also be developed to monitor changes in participant outcomes and provider performance where supports are delivered under new pricing and payment approaches.

Figure 134: The four elements of a new pricing and payments framework

1

Strengthened reporting and information

- Require providers (with appropriate exemptions for smaller and enrolled-only providers) to report *(Recommendation 11)*:
    - o relevant financial information to inform NDIS price caps
    - o accurate, up-to-date information on the prices they charge for NDIS supports, which should be published on the centralised online platform
- Publish information on the performance of registered providers *(Recommendation 12)*, including on the centralised online platform

2

Pricing and payment approaches that reward providers for delivering quality supports to participants

- Implement robust price setting processes, including a data-driven approach to estimating market prices for a support subject to a price cap *(Recommendation 11)*
- Introduce a range of payment approaches to better reward providers for the value of supports delivered, rather than the volume of supports delivered – including designing, testing and evaluating outcome payments for suitable supports to strengthen incentives for providers to deliver outcomes for participants *(Recommendation 11)*
- Progressively roll out preferred provider lists to better leverage government buying power for capital supports *(Recommendation 11)* and provider panel arrangements to pool and coordinate demand for allied health supports in small and medium rural towns *(Recommendation 13)*

3

Transparent, predictable and aligned price setting

- Transition responsibility for advising on NDIS pricing to the Independent Health and Aged Care Pricing Authority (IHACPA) to strengthen transparency, predictability and alignment of NDIS pricing (Recommendation 11) and ensure:
    - o price caps are robust, transparent, and strengthen confidence in the price setting process, by leveraging IHACPA's existing capabilities
    - o greater alignment when setting prices across the care and support sector to ensure government does not compete with itself and makes better use of its buying power

4

Dynamic feedback loops in the calibration of budgets

- Make it easier for participants and their Navigators to monitor spending and manage funding *(Recommendation 10)*
- Transition to fully electronic payments and improve visibility of NDIS payments to give governments the information required to be effective market stewards, understand what works and deliver outcomes, and strengthen scheme integrity *(Recommendation 10)*
- Index participant budgets at 1 July each year following price reviews *(Recommendation 3)*
- Undertake more active, evidence driven market monitoring to identify issues with access to quality supports *(Recommendation 13)*

The proposed pricing and payment framework would need to be regularly refined as reforms to the scheme are implemented and in line with changes in NDIS markets and the broader care and support environment.

4.6.1 Strengthened reporting and information

The NDIA's Pricing Arrangement and Price Limits document is the only comprehensive list of NDIS prices that is publicly available. But it is not easy for participants to understand, and only outlines what the price caps and rules are. There is no requirement for providers to publish a price list for the full set of services they offer, with the exception of providers claiming TTP for certain supports.

This contrasts with other social services, where price information is more readily available to consumers and governments. For example, the aged care *Home Care Package Program* requires providers to publish a price list on the *My Aged Care* website for the full set of services they offer.[1955] The NDIA has suggested that neither the NDIA nor NDIS Commission are able to require providers to publish their prices.

More than a decade ago, in 2007, price disclosure arrangements were introduced in the Pharmaceutical Benefits Scheme (PBS).[1956] Suppliers of certain medicines on the PBS were required to disclose the actual prices at which their medicines were sold – including both their sales revenue and volume. Critically, the arrangements included a feedback loop that allowed the prices of PBS-listed medicines to be adjusted to better reflect the average actual prices paid by pharmacies.

> *"Price disclosure requirements can improve the understanding of the market efficient price and support evidence-based decision making in price regulation. Improving data collection and stratification of payments and pricing should allow for the realisation of the market efficient price for more services, eliminating scope for inappropriate charging. Where appropriate, price ranges should be narrowed or removed in mature markets delivering generalised services with low scope for innovation to improve participant or scheme outcomes." – National Disability Services[1957]*

Requirements for providers to disclose relevant financial information should be strengthened to collect more data on costs of delivering supports and services. Appropriate exemptions may be made for smaller and enrolled-only providers. This would ensure the requirements to disclose financial information are proportionate to the risks, size and complexity of supports and services being delivered. The actual prices charged by providers should be published on the centralised online platform (see Action 10.1) so participants can make more informed choices about supports.

Participants who have the capability and desire to self-manage all their supports would not be subject to price caps. Transitioning to a fully electronic payment system (see Action 10.3) presents opportunities to capture more information on actual prices of supports for all NDIS transactions (including self-managed supports). A multi-channel digital NDIS payment system (see Action 10.1) would make it easier and faster to pay their providers through the system and more information would be captured on prices paid for self-managing participants. This would be especially important to see where participants have been able to get better deals for NDIS supports and

services, and should inform the price setting process and development of any new pricing and payment approaches.

Together, improved data collection would be able to inform a better understanding of the actual costs incurred by providers when delivering supports and services and how these costs change over time.

Drivers of these costs could also be better understood. Costs of regulation would be easier to factor in under a more risk-proportionate model of provider regulation (see Recommendation 17) that aligns enrolment and registration requirements to the risk associated with the nature of delivering different supports and services.

More active, evidence-based market monitoring (see Action 13.1) would support a more data-driven approach to appropriately differentiate price caps to improve supply and access to quality supports for participants. This could include differentiating price caps to account for the costs of delivering supports to participants with more complex needs, in different regions, and in group-based settings.

4.6.2   Pricing and payment approaches that reward providers for delivering quality supports for participants

Using a fee-for-service payment approach for all supports and services fails to design market settings that appropriately recognise the diversity and nature of NDIS supports and services. In doing so, the NDIA fails to align the incentives for providers with participants' and governments' interests in optimising value for participants and the scheme.

Instead, a range of payment approaches (Figure 135) should be carefully designed, tested and introduced considering the needs and characteristics of participants, providers and nature of supports. These payment approaches should improve incentives for providers to deliver quality and effective supports that benefit participants, rather than only paying for the volume of supports delivered.

For some supports (such as home modifications, AT and consumables), a fee-for-service payment approach may still be appropriate. However, government buying power could be better leveraged across government-funded programs using preferred provider lists (see Action 11.2).

Where relevant, user-friendly and standardised service agreements (or deeds) with governments could be used to cover repairs and maintenance for AT supplied by preferred providers. These could similarly be used to enable participants to hire AT to meet short term or changing needs.

An ongoing monitoring and evaluation framework would also be needed to monitor changes in participant outcomes and provider performance where supports are delivered under new pricing and payment approaches.

Figure 135: Pricing and payment approaches to improve incentives for providers to deliver quality supports for participants

Pricing and payments

Who chooses the provider whom the payment goes to?
- **Participant** – i.e. person receiving the support or service
- **Community** on behalf of participants
- **Government** on behalf of participants

What is being delivered, and how is it paid for?
- **Fee-for-service payment** for a unit of a support or service
- **Activity-based payment** for a group or range of supports (or activities)
- **Enrolment payment** for supports provided over a period of time
- **A blend (or mix) of payments** including an outcome payment for achieving an outcome or performance measure

How much can be paid for the supports or services?
- **No price regulation** for fully self-managed participants
- **Price caps** to set the maximum amount allowed
- **Quotation requirement:** price up to the approved quote
- **Contracted prices:** prices as agreed in contract

4.6.3   Transparent, predictable and aligned price setting

To ensure transparency in setting prices, advice on what price caps should be set should be independent from the NDIA as they are the funding body. Instead, IHACPA should be responsible for advising the Australian Government on the suitable indicators of the market price and price caps for relevant NDIS supports.

Prior to formally taking on the role in advising on NDIS price settings, IHACPA should undertake a costing study and a 'shadow pricing' process. IHACPA should undertake an initial costing study for development of any new pricing and payment approaches (see Action 11.1). As it has done in aged care, IHACPA should also use a 'shadow pricing' process to accurately model the impact of changes

to a new pricing and payment approach and minimise the risk of undesirable, unintended consequences.[1958]

IHACPA's advice to the Australian Government should inform price caps for NDIS supports from 1 July 2026. The Australian Government, in consultation with state and territories governments, should make the final determination on the prices for NDIS supports, based on IHACPA's advice.

In transitioning to a fully electronic NDIS payment system, increased visibility of all NDIS transactions (particularly self-managed supports) could also inform where NDIS markets could transition to lighter touch price regulation approaches in the future.

4.6.4   Dynamic feedback loops in the calibration of budgets

Transitioning to fully electronic payments (see Action 10.3) would not only assist governments with a more data-driven approach to pricing and payments, but would also support participants and their Navigators to track spending and manage their funding. More accessible, timely and reliable information would support participants and their Navigator (where needed) to know what funding they have used and have remaining so that participants can make more informed spending decisions.

Greater visibility of NDIS markets (see Recommendation 10) and more active, evidence-based market monitoring (see Action 13.1) would enable the Australian Government, supported by advice from IHACPA (see Action 11.3), to monitor market behaviour to identify:

- whether the pricing and payment approaches are working as intended. This includes where there may be unintended consequences or perverse incentives for providers.
- where pricing and payment approaches need to be adjusted and refined. For example, where price caps need to be indexed as part of annual price reviews, past spending can help inform how NDIA appropriately index participants' more flexible budgets (see Recommendation 3).

This would also support governments to more effectively steward markets. Governments would be able to identify where there are emerging and persistent market gaps, and what actions they need to take to address these market gaps. For example, this includes where challenges in NDIS markets cannot be addressed by pricing and payment approaches alone (see Recommendations 13 and 14).

4.6.5   Reviewing and refining the pricing and payments framework

The proposed pricing and payments framework cannot be just 'set' without ongoing monitoring and refinement. As reforms to the scheme are implemented, there will be changes in NDIS markets and the broader care and support environment.

- Participants should be more supported to act as informed consumers with more accessible, timely and reliable market information (see Recommendation 10) and more dedicated and graduated support to navigate the scheme and NDIS markets (see Recommendation 4).

- More flexible budgets with a plan of action of how supports could be used (see Recommendation 3) and with more transparency over what providers charge (see Action 11.1) should also see participants become more price responsive.

- A more risk-proportionate model of regulation (see Recommendation 17) with metrics published on provider performance (see Recommendation 12) should see more providers compare and benchmark their service offerings, uplift in quality and greater innovation in how supports and services are delivered.

- Greater market visibility should also enable Australian Government to better evaluate the outcomes and functioning of the self-managed market, with the data collected through fully electronic payments (see Action 10.3).

While these changes will take some time to implement and to bear fruit, the Australian Government should not wait too long to review the new pricing and payments framework. Instead this framework should be reviewed and refined regularly – for example, every five years – to ensure pricing and payment approaches remain suitable for the changing NDIS environment and broader care and support sector.

4.6.6   Action & Implementation Details

Action 11.1: The Department of Social Services should develop a new NDIS pricing and payments framework to be administered by the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority, including better ways to pay providers to promote the delivery of efficient and quality supports and continuity of supply

The new framework should enable price caps to reflect the market price for delivering supports, including for participants with more complex needs, in different regions, and in group-based settings. The implementation of the framework should be data-driven with strengthened requirements for providers, with appropriate exemptions for smaller and enrolled only providers, to disclose relevant financial information and the prices they charge. The framework should also enable payment approaches that strengthen incentives for providers to deliver 'value-based' supports that help participants to achieve outcomes. As part of the new framework, fully self-managed participants or their nominees who are capable of and choose to manage their own funding should not be subject to price caps.

Implementation detail:

- Providers should be required (with appropriate exemptions for smaller and enrolled-only providers) to:

  - report relevant financial information to inform NDIS price caps

- disclose accurate, up-to-date information on the prices they charge for NDIS supports, which should be published on the centralised online platform (see Action 10.1).

- The process for setting price caps should be clear, transparent and based on the market price for delivering supports, including any costs associated with regulation (see Recommendation 17).

- A data-driven approach should be used to appropriately differentiate price caps to improve supply and access to quality supports for participants. Price caps should be differentiated to account for the costs of delivering supports to participants with more complex needs, in different regions, and in group-based settings.

- A range of payment approaches should be designed and implemented to better reward providers for delivering effective supports that benefit participants, rather than only paying for the volume of supports delivered. This should include:

  - where suitable, activity-based payments (for a defined group of services or 'activity') as well as other payment approaches.

  - enrolment payments, which in time could include an outcome-based payment, for shared living supports (see Action 9.2).

  - designing, testing and evaluating outcome-based payments for suitable supports to strengthen incentives for providers to deliver outcomes for participants. This should commence with rolling out an approach to measure and publish metrics of registered provider performance (see Action 12.3).

- The development of new pricing and payment approaches should be informed by an initial costing study undertaken by the Independent Health and Aged Care Pricing Authority (see Action 11.3).

- An ongoing monitoring and evaluation framework should also be developed to monitor changes in participant outcomes and provider performance where supports are delivered under new pricing and payment approaches.

Action 11.2: The <u>National Disability Insurance Agency</u> should progressively roll-out preferred provider arrangements for capital supports to better leverage its buying power and streamline access for participants

This should include home modifications, assistive technology and consumables. Preferred providers should be paid a fee-for-service payment negotiated by the National Disability Insurance Agency (NDIA), reflecting the one-off, irregular and more transactional nature of capital supports. The NDIA should consider opportunities to work with other government agencies to further increase buying power across government-funded programs. Preferred

provider arrangements should also include, where relevant, published, user-friendly, and standardised service agreements covering maintenance and servicing, as well as loan arrangements for assistive technology required for short periods.

Implementation detail:

- The NDIA should ensure preferred providers remain responsive to participants by allowing:

  - other providers to join the preferred provider arrangement at any time if they are willing to provide supports at the negotiated or lower price, with the same or higher service quality.

  - participants to purchase from other providers using a quoting approach. The NDIA should accept quotes that are in line with the price, quality and consumer protections of preferred provider arrangements.

  - participants to purchase low-cost and frequent use capital supports from other providers in cases where the preferred providers have no or limited availability.

    o For low-cost assistive technology and home modifications, participants could purchase from other providers without using a quoting approach when the item is below a defined threshold per item.

    o For consumables, participants could purchase from other providers without using a quoting approach up to a defined threshold per year.

    o Implementation of these thresholds should be monitored and revised, as needed.

Action 11.3: The Australian Government should transition responsibility for advising on NDIS pricing to the Independent Health and Aged Care Pricing Authority to strengthen transparency, predictability and alignment

The Independent Health and Aged Care Pricing Authority (IHACPA) should be responsible for advising on suitable indicators of the market price and price caps for relevant NDIS supports. IHACPA should consult with the Department of Social Services, the NDIA, the National Disability Supports Quality and Safeguards Commission, state and territory governments, and the broader sector when advising the Australian Government on prices. Expanding the remit of IHACPA to include NDIS pricing would support greater alignment across the care and support sector and ensure government does not compete with itself and makes better use of its buying power across sectors.

Implementation detail:

- The Australian Government, in consultation with state and territory governments, should amend the legislation for IHACPA and confer upon it functions relating to NDIS pricing

and costing matters. In alignment with this new function, IHACPA should be renamed to reflect the NDIS pricing role. IHACPA should be resourced adequately and be able to access additional expertise, such as in relation to pricing regulated assets, to perform this pricing function, including pricing for Supported Disability Accommodation (SDA) (see Action 9.5).

- IHACPA's approach to pricing should be informed by the pricing and payments framework (see Action 11.1). This should include using a data-driven approach to estimate market prices for supports subject to a price cap, and be informed by providers reporting relevant financial information.

- The SDA pricing framework should also be revised to allow flexibility for IHACPA to price certain dwellings above the price cap by exception (see Action 9.5).

- IHACPA should undertake a costing study and 'shadow pricing' process prior to formally taking on the NDIS pricing role.

- IHACPA's advice to the Australian Government should inform price caps for NDIS supports from July 2026.

- The Australian Government, in consultation with state and territories governments, should make the final determination on the prices for NDIS supports, based on IHACPA's advice.

Action 11.4: The <u>Australian Government</u> should review and refine the pricing and payments framework once underpinning reforms have been implemented

This should consider the suitability of the framework based on changes in the NDIS market that result from implementing reforms to participant budget setting, dedicated and graduated assistance with navigating the NDIS, information including quality and safety measures, and improved incentives for providers. It should also evaluate the outcomes and functioning of the self-managed market, with improved data and market visibility through fully electronic payments (see Action 10.3).

Implementation detail:

- The <u>Australian Government</u> should evaluate the impact on the functioning of NDIS markets of actions to:

  - provide more accessible, timely and reliable information for participants and Navigators to easily compare providers based on the price, quality and safety of supports; and improve visibility of all NDIS transactions (including for self-managed supports) by transitioning to fully electronic payments (see Recommendation 10).

5. Market monitoring and coordinating NDIS markets

- Moving to a market-based model, where funding follows the participant and not the provider, has shifted responsibility of coordinating access to supports from governments to participants, their families, providers and intermediaries. Understanding how NDIS budgets can be used to get the best outcomes takes a lot of time. In some NDIS markets, participants, their families, providers and intermediaries have not had the capacity or capability to coordinate supports in a complex, changing NDIS environment.

- A lack of effective market coordination has meant some NDIS markets have not generated sufficient 'thickness' to function well and deliver outcomes for participants. In these thin NDIS markets, it has often been difficult for participants to find suitable service providers, and for providers to achieve economies of scale and to ensure continuity of supply.

  - Outside remote and very remote Australia, there are also market gaps in access to capacity building supports in medium and small rural towns (MMM 4 and MMM 5).

  - There is a lack of transparent policies and processes ensuring participants continue to have access to supports should NDIS markets fail.

- To date, efforts to steward markets and improve access to supports have been too narrow. Attempts to use a more active, flexible and tailored approach to stewarding markets have been hindered by a lack of comprehensive, accurate and timely information about who is in NDIS markets, what is happening in these markets and who is responsible for stewardship.

- Strengthening access to safe and quality supports for all participants would require governments to undertake more active, evidence-based market monitoring and to use a range of responses flexibly to address identified market challenges. There also needs to be clear accountabilities, including when these are shared. Governments, with local intelligence from Navigators and improved visibility of all payments, should be able to better identify where participants are facing persistent challenges accessing supports.

- Participants and their Navigators should also have access to tools that help them connect with others who have similar support needs and preferences. New matching tools can help participants and their Navigators to pool their demand and combine their buying power to

influence better responses from NDIS markets. As a group, they could encourage providers to deliver services in a way that better meets their collective support needs and preferences.

- In other NDIS markets, competitive approaches have not been able to ensure access to quality supports. More contestable approaches are needed, and should include:

  - Setting up provider panels in small to medium rural towns to ensure participants have better access to allied health supports where they live.

  - Establishing transparent provider of last resort policies and processes for appropriate and timely responses to failure in NDIS markets.

Recommendation 13: Strengthen market monitoring and responses to challenges in coordinating the NDIS market

- Action 13.1: The <u>Australian Government</u> should undertake more active, evidence driven market monitoring to identify issues with access to quality supports early and take more timely and appropriate action.
- Action 13.2: The <u>National Disability Insurance Agency</u> should progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps.
- Action 13.3: The <u>National Disability Insurance Agency</u> should develop matching tools to support participants and Navigators to pool demand for supports.
- Action 13.4: <u>All Australian governments</u> through the <u>Disability Reform Ministerial Council</u> should agree and publish a provider of last resort policy to ensure participants have continued access to supports where markets fail.

5.1. More active, evidence-driven market monitoring is needed for proactive identification of emerging market issues and for timely, appropriate intervention

A limited capacity to monitor markets limits governments' ability to take a more active, flexible and tailored approach to stewarding NDIS markets.

Without sufficient and timely market data (see Section 2.1.3), governments do not have the critical information to know when they need to intervene and to know what market interventions would be effective to ensure NDIS markets are functioning well and delivering outcomes for participants.

5.1.1 Limited market visibility and unclear processes to raise emerging market issues hinders governments in improving coordination and collaboration in NDIS markets

Governments' current market monitoring approach is largely informed by administrative data on participant spend, plan utilisation and ratios of participants to providers.[1959] This is based on incomplete visibility of the market (see Section 2.1.3). Very little local market intelligence is actively and systematically collected from Local Area Coordinators, Remote Community Connectors or

Support Coordinators about what is happening in local NDIS markets, and used to inform market monitoring.

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Box 71: Currently there is no systematic or comprehensive way of monitoring providers exiting NDIS markets and withdrawing services

Governments' limited visibility of NDIS markets includes who is exiting NDIS markets or withdrawing services. Governments do not have a systematic and comprehensive way of monitoring when a provider is exiting or withdrawing services from NDIS markets.

Only registered providers are currently required to notify the NDIS Commission if they are withdrawing services or exiting the market.

- During the 2022-23, 74 registered providers notified the NDIA that they were either ceasing delivery of all NDIS supports (34 providers) or some NDIS supports (40 providers), which affected around 9,000 participants.[1960]
- No feedback is collected from participants who have been supported through the provider exit process.

Unregistered providers do not face the same reporting requirements, even though 43 per cent of all plan-managed payments were made to over 154,000 unregistered providers in the quarter ending 30 June 2023.[1961]

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As such, it is difficult for governments to identify emerging or persisting gaps in service delivery (or 'market gaps') and to gauge whether NDIS markets are delivering outcomes for participants. It is even more challenging to know if pricing and payments approaches are working, whether (or how) the pricing and payment approaches need to be adjusted, or what other market interventions may be needed.

Publicly available data on NDIS markets is not sufficiently detailed for communities to raise issues or respond to emerging and persistent market gaps. While the NDIS Demand Map is a good start in sending more proactive signals to the market about the future demand for supports, more is needed from governments for prospective providers to understand where and what opportunities exist in NDIS markets.[1962]

Public information on governments' approach to identifying, prioritising and intervening in markets is also limited, and in some cases, outdated. [1963] This means that it is often unclear how participants and providers can raise concerns about emerging market issues or thin markets. It also creates uncertainty about the continuity of supply when markets fail.

Without improved market visibility to monitor emerging market gaps or opportunities, governments' ability to take a more active, flexible and tailored stewardship approach is hindered. As market stewards, governments are also not be able to send timely, accurate signals about

emerging market gaps or opportunities (see Section 2) to participants and providers in NDIS markets.

5.1.2   Increased market visibility paired with local intelligence would support more active, evidence driven market monitoring

It is clear that improving governments' capacity to monitor NDIS markets is a priority.

A number of our recommendations would strengthen governments' visibility over NDIS markets. The proposed risk-proportionate regulatory model (see Recommendation 16), the transition to fully electronic payments (see Action 10.3) and more secure two-way information-sharing with third party online platforms (see Action 10.2) would provide governments with more complete data on how NDIS markets are working for participants and providers. Navigation supports for all people with disability (see Recommendation 4) would supplement data collection with much needed local market intelligence.

At the same time, market data collection should not impose an undue burden on participants, providers and Navigators. Any information collected should have a clear purpose to help:

- improve governments' understanding of how NDIS markets are working for participants and providers
- identify when governments need to intervene or take action in NDIS markets
- inform what interventions or actions governments should take, including through improved local level information.

5.1.3   Action & Implementation Details

Action 13.1: The <u>Australian Government</u> should undertake more active, evidence-driven market monitoring to identify issues with access to quality supports early and take more timely and appropriate action

Market monitoring should draw on improved data collected from the transition to fully electronic payments (see Action 10.3) and information on service access issues reported by Navigators (see Recommendation 4). The National Disability Insurance Agency, in consultation with other government agencies, should use this information to take action to address market challenges and persistent and emerging supply gaps. This should include regularly releasing local market monitoring information to Navigators and providers (including, for instance, the NDIS Demand Map).

5.2. Addressing market gaps also calls for improved market coordination and collaboration in the scheme using a range of tools

NDIS markets need to have sufficient thickness to function. However, some NDIS markets have not been able to generate sufficient 'stickiness' and/or depth without more active market coordination. In these markets, many participants are left with little help to coordinate demand for supports and services, and limited to no access to supports they need.

While competitive approaches have important benefit to participants exercising choice and control, competition between multiple service providers in the market will not always be possible. To function well, some NDIS markets will need a range of tools – including contestable approaches – to generate sufficient thickness and ensure participants can access NDIS supports where they live.

5.2.1 A range of market access settings which can be used to ensure access to safe and quality supports

Settings around market access determines who can enter a market to deliver supports to service recipients or consumers.

In NDIS markets, these settings determine which providers can deliver specialist disability supports or services to participants. The regulatory model for delivering disability supports would determine the relevant quality and safeguarding regulatory requirements which all providers would need to comply with. Different settings around market access could require some providers to meet additional requirements on top of these.

Approaches to determining market access settings can be 'competitive' or 'contestable'.

Box 72: What are competitive approaches?

Under a competitive approach, providers *compete in the market* to deliver supports to individual people, or a 'share' of the market.

- Participants can often choose from multiple service providers, who each offer similar supports and services to each other.
- A provider can join or exit the market at any time. While there might be requirements or standards that providers need to meet to deliver services, barriers to entering and exiting the market are lower. For example, providers can decide to exit a market if it is no longer viable to deliver services, even though there are people who still need their services and no other providers are delivering services in this market.
- While governments (as regulators) monitor and enforce compliance against quality and safeguarding arrangements, participants also play a part in determining who can stay in the market. Participants "vote with their money" by switching from providers who deliver low quality, low value or potentially unsafe services, towards providers who deliver safe, high quality supports that are better value for money.

However, competition between multiple service providers in the market will not always be possible. Competitive approaches may not be enough for providers to be responsive in delivering the supports which participants need in the way that they want. In these situations, more contestable approaches are needed.

"In [building a collective or individual service design that works for the group or community], in the context of the Scheme goal of social and economic participation, a smaller choice of providers offering services that have been designed through the participant voice, will be a more effective market than a larger choice of providers offering services that do not reflect the participant voice in their design." – JFA Purple Orange[1964]

Box 73: What are contestable approaches?

A contestable approach is where providers *compete for a market* – that is, providers compete with each other to deliver supports or services for all people in the market. Typically, 'the market' – which providers are competing for – needs to be defined first:

- The market does not need to be very big. It could cover a specific type of support for a defined group of participants (such as physiotherapy support for NDIS participants living in a small rural town). It could also be a 'bundle' of supports or 'wrap-around' supports for individual participants or a group of participants.
- The market could also be defined at the 'whole of market' or 'whole of community' level. For example, it could be for all NDIS supports in a remote community or all NDIS supports for a First Nations community in metropolitan or regional area.

How do contestable approaches work?

Like with all decisions around market design and settings, contestable approaches should be designed considering the collective needs of participants, the nature of supports as well as the characteristics of providers. In this way, even where there is just a single provider, contestable approaches can ensure providers are responsive to participants' needs and preferences, without experiencing the drawbacks of competition when the conditions for effective competition are not met.

- A contestable approach can have a single provider or more than one provider. Participants can only choose from the providers engaged under the contestable approach. There usually would be very few providers delivering similar supports or services to each other. For example, participants could have two providers to choose from but one delivers speech therapy and the other delivers physiotherapy.
- Providers cannot enter the market (to deliver supports), nor can they exit, at any time. Instead, their performance is evaluated usually after a set time period, and there would be a credible threat of replacement if they are not performing in line with the expected

standard – that is, if the provider is providing poor quality services or not delivering outcomes for participants, they would be replaced by a better performing provider.

- Governments typically are responsible for monitoring and evaluating the performance of the provider(s). However, there are usually also formal mechanisms for participants and communities to provide their feedback on the performance of the provider(s) to inform government decisions.

There are a range of competitive and contestable approaches that can be used in NDIS markets to ensure all participants have sustainable access to safe, quality supports. These would not replace the requirement for providers to enrol or register and to comply with the relevant quality and safeguarding regulatory requirements (see Recommendation 17).

Figure 136: Governments need to use a range of market access approaches to ensure participants have access to safe, quality and sustainable supports

Market Access

Who can deliver supports?

Providers who are registered or enrolled, in line with the graduated and risk-proportionate regulatory model

(This is a requirement of all providers, regardless of any additional market access requirements)

- Registered providers have additional requirements proportionate to risk, including attestation and/or assessment of compliance with relevant Practice Standards, and suitability assessment

- Enrolled providers attest to understanding obligations under the Code of Conduct and worker screening requirements

Preferred provider lists: Participants can choose **any provider, including preferred providers**. Preferred providers have an agreement with government to deliver supports (such as for capital supports) at a better price with agreed standards.

Service agreement or deed with government: Participants can choose **from providers who have signed up to the agreement or deed with government**, where providers agree to deliver supports in a specific way or to a specific standard. Providers can sign up at any time to do this.

Competitive approaches: Providers compete **in the market** to deliver supports to participants

Provider panel: Participants can **only choose from providers on the panel**, which are arrangements with a group of providers to deliver specific supports or services. Provider panel arrangements may specify that providers deliver supports using a certain approach, for specific locations and/or for specific needs. These arrangement are regularly monitored and re-tested.

Alternative commissioning: Participants in community can **only choose the commissioned provider(s)**, who have long term contracts to deliver supports or services using a certain approach, in select locations, and/or for specific needs. These arrangements should be explored, designed and implemented in partnership with the communities who they are delivering support to.

Provider of last resort: Participants would receive supports or services **from the provider of last resort when no other provider can deliver services**. The provider of last resort is contracted by governments to deliver supports for specific circumstances (e.g. when markets fail), usually as a last resort.

Contestable approaches: Providers compete **for the market** to deliver supports to participants

Preferred provider lists are an example of a competitive approach (see Section 4.5.2). Governments may negotiate a deal or an agreement with one or more providers to deliver specific supports at better prices with additional agreed standards and which could be below the relevant price cap. The providers are called 'preferred providers' or 'preferred suppliers'.

Where there are preferred provider lists, any provider who meets the requirements under the risk-proportionate regulatory model (see Recommendation 17) can still access the market to deliver supports or services. Participants can still choose any other provider in the market if they want to. However, the support or service may be delivered at a lower quality or standard or the participant may need to pay a higher price (as long as the price is below any applicable price caps, and the participant can afford to do so within their budget). In this way, participants would be encouraged to choose a preferred provider to get a better deal or better value for their money. Providers would also have incentives to deliver supports at a better price or quality, and to join the preferred provider list.

Governments could establish a service agreement or deed which providers have to sign up to in order to deliver certain supports or services. The service agreement or deed with the government would require providers to agree with its terms and conditions, which would specify service delivery requirements, such as the way providers should deliver supports in line with best practice. These requirements are on top of relevant quality and safeguarding regulatory requirements, and prospective providers could sign up at any time.

As an example, these government service agreements or deeds would be similar to how early childhood education and care providers operate in Australia.[1965] Governments set out specific requirements, standards and processes that providers must comply with to deliver early childhood education and care services. Prospective providers can sign up at any time. Once they demonstrate they have met the relevant requirements and standards, the provider has 'approval' or 'license' to deliver early childhood education and care services. A child's family can choose any early childhood education and care provider based on their needs and preferences (such as opening hours, location, type and quality of service, and additional services provided)[1966].

In NDIS markets, governments should use service agreements or deeds to ensure providers adopt effective and sustainable pathways of delivering supports which achieve outcomes for participants. This should include service agreements for early intervention psychosocial supports (see Recommendation 8), to cover the bundle of shared living supports and service expectations (see Recommendation 9), as well as maintenance and servicing requirement for preferred providers of capital supports (see Recommendation 11).

Under these service agreements or deeds set by governments, providers would be able to sign up and enter the market any time. The government service agreement or deed would not guarantee providers a share of the market – they would still have to compete with each other to deliver supports and services.

Participants should be able to choose any provider who has signed up to the government service agreement or deed. Participants, with help from their Navigator where needed, would still be able

to have their own service agreements with a provider that outline what supports or services would be delivered, and how much would be paid for the supports or services.

Yet, in some markets, these market access settings would not be enough to ensure access to safe and quality supports for all participants. Competition between multiple providers may not occur or may not be possible in markets where the supply or availability of supports is too low, or the demand for supports is too low or dispersed.

Where the conditions for strong market competition do not exist or are hard to sustain, contestable approaches can help ensure providers are responsive to the support needs of participants.

Provider panels, for example, could be used by governments to ensure all participants have access to safe and quality supports in a specified market (see Section 5.4). Similar to service agreements or deeds, governments would set up an agreement or arrangement with a group of providers to deliver specific supports or services. Provider panel arrangements would similarly specify service delivery requirements (such as using a certain approach). However, there are a few key differences:

- Provider panel arrangements may specify that the group of providers deliver supports or services in a select location or for specific needs.
- Participants would only be able to choose from the group of providers if they have certain needs, and live (or are receiving services) in a select location.
- Providers can only be selected to be on the panel at periodic time intervals (usually after a few years), when the providers' performances are evaluated and these panel arrangements are retested.
- Providers have more certainty and assurance of demand, and more incentive to work collaboratively together and better ability to share costs in delivering services.

In other thin markets, alternative commissioning arrangements may be needed. Rather than individual participants buying or purchasing services, alternative commissioning arrangements purchase supports for a group of participants or all participants in a community. Both provider panels and alternative commissioning arrangements ensure all participants have access to safe and quality supports in these markets.

However, compared to provider panel arrangements, alternative commissioning arrangements are usually longer term. This is to give providers the assurance of demand, time and resources needed to build their capacity and capability for sustainable service delivery. Often, commissioned provider(s) will need the time and resources to properly invest in the infrastructure, capital works, building local workforce capacity and capability need to sustain delivery of supports and services in the long term. The different types of alternative commissioning arrangements and how they can be used to improve access to supports are discussed further in Section 6.

5.2.2 Over-reliance on competitive approaches is leaving participants without access to supports across many NDIS markets

Past reviews of the NDIS indicate a range of ongoing market challenges and supply gaps that reflect more than just transition issues. Moving from block funding devolved responsibility for coordinating access to support from governments to individuals and the market. The shift relied on individual participants, their families and market intermediaries having the capacity and capability to do this in an already complex environment, with little (or at least unclear) protection for participants where markets fail.

For some NDIS supports, competition between multiple service providers has not been able to effectively ensure access to supports for participants. When demand for supports or services is too low or spread out, it is often difficult for providers to achieve economies of scale and to sustain supply of these supports. Having too few or no providers who are available to deliver supports makes it difficult for participants to find and match with suitable service providers. In these thin markets, participants are left with limited, or no, access to supports or certain types of supports.

> **Box 74: What is a thin market?**
>
> A thin market is a market where the supply or availability of supports is too low, or the demand for supports is too low or spread out for competition between multiple providers to occur.

Figure 137: Past reviews of the NDIS indicate a range of ongoing market challenges that reflect more than just transition issues[1967]

Limited access to supports in remote and very remote areas

"An issue for participants in rural and remote areas is a lack of service providers to provide the supports that participants are funded for in their plans, leading to low plan utilisation rates and the possibility of a decrease in funding in participants' subsequent plans. As a result, service providers that do exist in rural and remote areas may feature long wait times and long waiting lists for services."

Joint Standing Committee on the NDIS (JSC) Inquiry into NDIS Planning (2020), Chapter 9

Lack of culturally appropriate care for First Nations communities

"Aboriginal and Torres Strait Islander participants in the NDIS faced significant difficulty in accessing services, which witnesses and submitters observed could be largely attributed to the lack of culturally appropriate and affordable services available, particularly in rural and remote areas."

JSC Inquiry into NDIS Workforce (2022), Chapter 5

Shortages of some supports in non-remote communities

"The key issues with the NDIS in my experience is that regional areas are poorly serviced by a market-based approach, especially when services are specialised. It does not matter if you have the funds if nobody will provide the service."

Participant quote from Tune Review (2019), p.122

Some participants are being left behind

"[The] NDIS pricing framework is not working for participants with high and complex needs ... some service providers are 'cherry picking' clients and potentially leaving some of the most vulnerable NDIS participants with no access to adequate services."

JSC Inquiry into Market Readiness (2018), Chapter 5

Limited capability of NDIA to identify thin markets

"Existing mechanisms to solve thin markets rely on participant complaints to the NDIA and/or NDIA monitoring of participant utilisation — which trigger thin market initiatives"

Queensland Productivity Commission Inquiry into the NDIS Market in Queensland (2021), p.256

Unclear protection of participants against market failure

"The NDIS should address thin markets by ... publicly releasing its Provider of Last Resort (POLR) policy and Market Intervention Framework discussed in the NDIS Market Approach: Statement of Opportunity and Intent as a matter of urgency."

Productivity Commission Review into NDIS Costs (2017), Recommendation 7.1

Due to the range of ongoing market challenges and supply gaps, some mature participants – that is, participants who have been in the scheme for over a year – are not accessing supports despite having the budget to do so. This is most stark in remote and very remote communities where around two in five mature participants – participants who have been in the NDIS for one or more

years – are not accessing daily activity supports, and over one in three are not accessing therapy supports (Figure 138).

Markets for certain supports are also thin in non-remote areas, particularly for specialised services like behaviour supports and for First Nations participants to access culturally safe supports.

Figure 138: Participants, who have been in scheme for over a year, are still not accessing the supports they need[1968]

Share of mature participants (in the Scheme for over 1 year) who have a budget but no payments in March 2023 quarter for specific supports:

Daily personal care activities supports

24% in metropolitan areas
26% in regional areas
27% in rural areas
34% in remote areas
44% in very remote areas

Supports that assist with skills and independence (therapy)

25% in metropolitan areas
30% in regional areas
32% in rural areas
33% in remote areas
36% in very remote areas

Why look at outcomes for participants who have been in the Scheme for over a year?

- When participants are new to the Scheme, utilisation rates are significantly lower in the first year as participants work out how the NDIS works, but this stabilises over time.

- It is therefore useful to compare access for participants who have passed the transition phase.

Why some participants may not be accessing some supports?

- Access issues are observed across both daily personal care and therapy supports, suggesting difficulties to access services is due to other reasons.

- Budgets may not align with support needs.

- Some may be accessing informal care.

- Some receive supports seasonally.

Note: Data as at 30 June 2023, allowing for a 3-month payment lag. In-kind supports are excluded.

As far back as 2017, the Productivity Commission found thin markets have been, and will continue to be, a persistent feature of the disability support sector. And in the absence of government intervention, there will be greater shortages, less competition, and ultimately poorer outcomes for participants.[1969]

5.2.3   Efforts to address market gaps to date have been too narrow

In 2019, the then Disability Reform Council (now Disability Reform Ministers' Council or DRMC) acknowledged the need to use a more flexible approach to address market challenges following the development of the NDIS Thin Markets Framework commissioned by DSS.

"The Council agreed to use a more flexible approach to address market challenges in the NDIS, recognising that a 'one-size-fits-all' approach to delivering the NDIS is not suitable to address market gaps faced by certain geographic locations, particular cohorts or disability support types." – DRC[1970]

The NDIA subsequently undertook 13 thin market trials across each state and territory as agreed by DRMC. A further 26 thin market projects were also initiated by the NDIA where potential supply gaps had been identified. The 39 thin market trials focused on improving market information, with some looking at assisting participants to pool funding and, in very few cases, trialling direct commissioning arrangements.[1971]

An internal evaluation of the trials found market information provision was not sufficient to overcome challenges in thin markets with some or mixed success seen when participants pooled their funding or where the NDIA directly commissioned supports.[1972] This implies more active interventions were needed, particularly to coordinate NDIS markets.

Findings from the evaluation indicated that coordinated funding proposals (CFPs) appeared to have had the most success in improving access to supports. CFPs provided a way for participants to connect with each other to increase their buying power in the trial locations. Through CFPs, participants could pool their demand by combining their funding and coordinating what services they collectively needed. Doing this helped participants to attract providers to deliver specific services, deepening the market.

However, CFPs need to be tested across a wider range of support types and locations. Most CFPs focused on one-off functional assessments and/or assessments to support ongoing therapies. Further, the success of CFPs were found to rely heavily on Support Coordinators working together collaboratively. The evaluation, however, highlighted mixed success in being able to get Support Coordinators to work together. This was reported to be a factor in some CFPs not proceeding.

Direct commissioning trials were only applied in a handful of circumstances and had mixed success. While the evaluation found that direct commissioning increased assurance of demand for service providers in the few trials undertaken, the increase in NDIS spending was marginal outside of the one very remote trial.

The NDIA thin market trials have also not addressed the underlying drivers of thin markets – particularly those driven by current market design and settings around pricing and payment approaches (discussed above) and market access – which has resulted in limited success in improving participant outcomes.[1973]

It should be noted that the evaluation of the thin market trials largely defined and measured success based on increased participant spending and budget utilisation. Some limited qualitative information was collected to gauge whether the market interventions "worked as intended".[1974] However, these measures may not reflect increased participant access to supports, nor whether the interventions sufficiently addressed the drivers of thin markets.[1975]

Figure 139: What did NDIA's evaluation of thin market trials find?

Market facilitation to improve connections between providers and participants, such as focused engagement and **sharing targeted market information**

- Market facilitation has featured in almost all 39 thin market trials since 2019.
- There is **no evidence that, on average, market facilitation trials increased participant use of NDIS supports or strengthened local NDIS markets** above all other activities undertaken by the NDIA or other market intermediaries.
- Feedback from service providers and support coordinators indicated that market facilitation activities were insufficient to encourage greater service provision and to overcome systemic market challenges – such as workforce shortages and participants' limited understanding of the NDIS.

Coordinated funding proposals (CFP) to enable participants to pool NDIS funding to more efficiently secure services from providers

- CFPs have been, or are being, trialled across nine remote and very remote communities.
- Trials have shown **success at pooling participant demand, particularly for participants to access one-off functional assessments.** CFPs help service providers – mainly based outside the community and travelling by road or air – to mitigate demand uncertainty, and share travel and administration costs. However, to understand the potential of CFPs, they need testing across a wider range of support types and locations.
- Main challenges with CFPs appear to be the logistical challenge for service providers to coordinate service delivery across multiple support coordinators who are not always based in the community.

Direct commissioning directly contracts providers to deliver support to a participant or a group of participants

- Only three trials used direct commissioning.
- **Only one trial was run in a remote context**, and it was limited to community, social and civic participation supports. While it is still too early to assess, **the NDIA expects a projected increase of around 119% (or over $10,000) in average annual participant expenditure for these supports.**
- For **non-remote trials**, direct commissioning **had only a marginal increase in use of NDIS supports** – that is, an increase of less than $250 per participant each year. Providers also reported **substantial financial and administrative burden** arising from additional claiming processes and reporting requirements.

Case Study 27: Mornington Island Thin Market Trial[1976]

The NDIA ran a CFP trial in Mornington Island, with over 20 participants residing in this very remote area, of which over 70 per cent identified as First Nations people. When the trial

commended in March 2020, average plan utilisation was 49.1 per cent, indicating severe market gaps and significant low utilisation of NDIS budgets.

As part of the trial, the NDIA conducted market facilitation activities for Support Coordinators and service providers. The NDIA also set up a CFP working group for participants' Support Coordinators. CFP helped to secure an allied health provider to fly in and deliver functional capacity assessments for 14 trial participants (as well as additional supports for participants not part of the trial).

The NDIA's evaluation of the trial found very little evidence that the market facilitation activities in the community had improved utilisation.

However, the NDIA also found that after 10 months of operating, the CFP had significantly increased participants' access to, and expenditure on, allied health supports. The average participant plan expenditure 12 months before the CFP commenced was $652, and 12 months post CFP it had increased to $7,027.

The NDIA attributed the increase in utilisation to the continuation of the CFP working group as a Support Coordinator community of practice. NDIA remote planners were heavily involved in facilitating and coordinating this group to identify and address service gaps in Mornington Island.

The internal evaluation of the NDIS thin market trials suggests sticking to a rigid focus on individualised funding arrangements and competitive approaches would continue to leave some participants without the supports they need.

> *"… rigid adherence to individualisation can have a negative effect, particularly when it is clear that some participants cannot access the supports they need, even when a robust market has been established." – Tune Review 2019* [1977]

Instead, we recommend using a range of market tools and approaches to address the coordination challenges facing many NDIS markets, including introducing:

- new ways for participants and providers to connect and for providers to work together more collaboratively to coordinate care and supports (see Action 10.3).
- more contestable approaches that can create sufficient 'thickness' to ensure all participants have access to safe and quality supports (see Action 10.2).
- provider of last resort arrangements to ensure continued access to critical supports should markets fail (see Action 10.4).

5.3. New ways are needed for participants and providers to connect, and for providers to collaborate

Generating sufficient thickness in some markets requires more 'stickiness' for connections in the market to form or deepen markets. These markets need more 'glue' for participants to enjoy the benefits of better coordination and collaboration between providers and systems.

5.3.1 New approach to delivering navigation supports is needed to improve coordination and collaboration in NDIS markets

The original vision for the scheme recognised that many people with disability would require an 'intermediary' to provide support to navigate the scheme and new NDIS markets that would emerge.[1978] For many people with disability, information alone would not be enough to find, choose and engage service providers (see Section 3.1). It was envisaged that participants would have access to an intermediary who would act as the 'glue' and play a role in helping to link up and coordinate the range of available funded supports, foundational supports and mainstream services.

In response, the scheme has introduced many different intermediary roles to help participants link to the supports they need. As outlined in the Chapter 2, each intermediary role delivers different functions in supporting participants to navigate the scheme and NDIS markets (see Recommendation 4).

Box 75: What is an intermediary?

An intermediary is an individual or organisation who acts as a 'middle person' in assisting participants to interact or engage with others, including providers. Intermediaries in the NDIS include roles such as: Local Area Coordinator, Early Childhood Partners, Support Coordinators, Remote Community Connectors and Plan Managers.

However, the current Partners in the Community program (which include Local Area Coordinator and Early Childhood Partners contracted by the NDIA) has not been implemented in a way to deliver on this vision (see Chapter 1). Funding and staffing constraints in the NDIA have led to Partners in the Community being diverted from their intended role to focus almost entirely on access and planning tasks. Very high caseloads have meant Partners in the Community spend limited time with each person (see Chapter 2). As a result, relationships have become transactional rather than relational, and people with disability are not being supported to achieve the outcomes that matter to them.

There has also been confusion around roles and responsibilities across various intermediaries in creating the necessary connections between participants and providers, particularly for the 65 per cent of participants who have access to more than one intermediary (see Chapter 2).[1979]

In different ways, introducing multiple intermediary roles has also hindered intermediaries – particularly Local Area Coordinators, Support Coordinators, and Specialist Support Coordinators – in how effectively they have been able to help participants in coordinating the range of supports available to them. Combined with the strict focus on competitive approaches and individualised budgets, the lack of functioning 'glue' may have contributed to eroding historical collaborative relationships among service providers, who often needed to work together to provide care coordination.

"... in this early stage of NDIS roll out service providers still perceived that the historical collaborative relationships of the past were largely being maintained. However there was also acknowledgement that a competitive environment was emerging and that this was already having some negative impacts on the ways in which information was being shared between organisations and the way staff were able to manage their time. These impacts have the potential to effect care coordination as this has traditionally relied upon integrated services which are able to collaborate and share information on clients." – Centre for Social Impact, UNSW Sydney[1980]

While a few communities of practice have emerged, there is also evidence that the current approach is hindering knowledge sharing and collaborative ways of working.

Introducing the new approach to delivering navigation support should address the confusions in current responsibilities (see Recommendation 4). All people with disability would have access to a Navigator, whose interests would more clearly align to the participants'. Navigators would have clearer responsibilities and accountabilities in facilitating the connections between participants and providers.

Supported by complementary recommendations on foundational supports (see Recommendation 1) and mainstream services (see Recommendation 2), Navigators would also have responsibility to coordinate supports for participants. This should foster more collaborative relationships between service providers and systems, which is needed to deliver care coordination.

5.3.2   New matching tools are needed to support participants to 'pool' demand for supports

The current narrow focus on competitive approaches has also not been conducive in encouraging a systematic approach to deepen markets by 'pooling' demand.

Moving to a competitive approach with individualised funding arrangements shifted responsibility for coordinating access to supports from governments to individuals and the market. However, participants, their families, carers and intermediaries have not had sufficient, accessible information or resources to easily do this (see Section 3.1).

While some channels exist for participants to connect with each other to share information, there is no systematic approach to pool demand to influence NDIS markets to respond (see Section 3.1). There are some channels (such as social media forums) for participants to broadcast their individual support needs and challenges in finding suitable supports. But these do little to broadcast a shared need for supports and potential gaps in availability of supports that can meet this need.

So where there are many struggling to find similar supports, participants, their families, carers and intermediaries have very few ways to find and connect with each other. This makes it difficult for participants to pool their individual funding and use their combined buying power to incentivise NDIS markets to respond.

Recent publication of information and resources on CFPs provide a way for participants, with help from their Support Coordinator, to pool their demand (see Section 5.2.3). But information about CFPs is hard to find. Given the success of CFPs seem to rely heavily on Support Coordinators working together collaboratively, CFPs are unlikely to be a scalable solution without channels to facilitate connections among participants, and their intermediaries where relevant, with similar support needs (Case Study 28).

Case Study 28: Community Managed Aged Care Model – the "Bell" model

In 2020, a local resident of Bell became concerned about the number of older residents without support and at risk of having to leave the town to move into residential aged care. While there were Commonwealth Home Support Programme (CHSP) providers in the nearby town of Dalby, there was no continuity of service and no local home care provider.[1981]

The local resident formed Bell Cares linked in with Mable and Trilogy Care. [1982]

- Bell Cares act as an intermediary to help local Bell residents to "self-manage" their home care plans.

- Trilogy Care is an approved aged care provider who offers self-managed home care plans. They help to engage local Bell residents as independent contractors, and support Bell Cares with the necessary clinical and financial governance in delivering home care services to the town.

- As a third party online platform, Mable provides a way for older Bell residents looking for care and support to connect with other local residents who can provide care.

In this way, Bell Cares, Mable and Trilogy Care have been able to work in partnership to match older residents needing care with other local residents who can provide care and support.

The Bell model, or Community Managed Care model, has now rolled out across multiple communities in Queensland and Western Australia. There are now over 400 older people and people with disabilities living in these small communities being supported by over 160 local self-employed support workers. [1983]

Governments need to do more to improve the reach and useability of CFPs. Building on the lessons in rolling out CFPs (see Section 5.2.3), participants and their Navigators will need new matching tools which:

- **can be used across a wider range of support types and across different locations**, not just for once-off assessments or assessments to support ongoing therapies.
- **support Navigators to work collaboratively together to pool demand** and choose a suitable service offering that best meets participants' collective needs. Coordinating participant demand will need to consider the support needs and preferences that are shared by all participants, and those that differ.

- **are easily accessible for participants and Navigators**. They should be made available online, such as via the centralised online platform (see Action 10.1) or other third party platforms (see Action 10.2).

For these to be scalable, these matching tools should be available and accessible online on platforms which participants and Navigators use to search for providers. These tools should allow participants and Navigators to connect with each other and build communities (Case Study 28). Together, they should more easily broadcast opportunities for existing and new providers to respond to their support needs and preferences.

If these are made available through the centralised online platform, governments could monitor their usage and provide additional protections around privacy, and quality and safeguarding.

5.3.3 Action & Implementation Details

Action 13.3: The [National Disability Insurance Agency](#) should develop matching tools to support participants and Navigators to pool demand for supports

New matching tools should assist participants and Navigators to connect with other participants where there is a joint benefit from pooling their budgets to find and purchase supports. This may apply to group-based and other innovative supports.

These tools should build on the lessons from the National Disability Insurance Agency's use of Coordinated Funding Proposals to provide more scalable online matching tools. Participants and Navigators should be able to easily access these tools, including via the centralised online platform (see Action 10.1). These tools should allow participants and Navigators to collectively broadcast opportunities for existing and new providers to respond to their support needs and preferences.

Implementation detail:

- As part of development of the centralised online platform (see Action 10.1), the National Disability Insurance Agency, in consultation with other Australian Government agencies, should commence designing and testing matching tools, which could also be expanded to be developed by the market. This design should consider the role of Navigators in assisting participants to pool their demand for supports.

5.4. More contestable approaches are also needed

In other NDIS markets, governments may need to do more to help participants and their Navigators to coordinate demand so they can access quality supports and have control and choice, where it does not exist today or exists in name only. For some supports (such as transport), delivery typically needs to be delicately configured to meet collective needs. In other markets, coordination may be needed across a number of supports, or for whole communities. In these NDIS markets,

more contestable market approaches would be needed to create sufficient 'thickness' to ensure all participants have access to safe and quality supports.

5.4.1 In rural areas, it is challenging for participants to access therapy supports where they live

Challenges in delivering supports and services to rural and remote communities are not unique to the scheme. However, it can be particularly challenging for participants to find and access suitable providers where the nature of supports often rely on have a trusted relationship with someone to deliver the supports or services face-to-face and on an ongoing basis.

Availability of suitable providers may be further limited where the person or people delivering the support or service also needs to be sufficiently skilled, qualified and/or experienced. We have heard there can be long wait lists and wait times for participants to access therapy services in regional and rural areas, and this can have downstream impacts on their ability to access other supports in their NDIS plan.

> *"I am in a regional area of 60,000. It is almost impossible to get services here for things such as OT's or speech pathologists – given these people are also required for approval of any spending – it is becoming quite unworkable." – Extracted Participant Quote from Australian Association of Psychologists Inc[1984]*

The current rigid focus on competitive approaches and individualised funding arrangements is likely to further exacerbating challenges in rural and remote service delivery. Without sufficient market coordination of often low, dispersed demand, these markets are unable to generate sufficient thickness and current market gaps are likely to persist.

Figure 140: Access to supports in rural and remote areas can be challenging[1985]
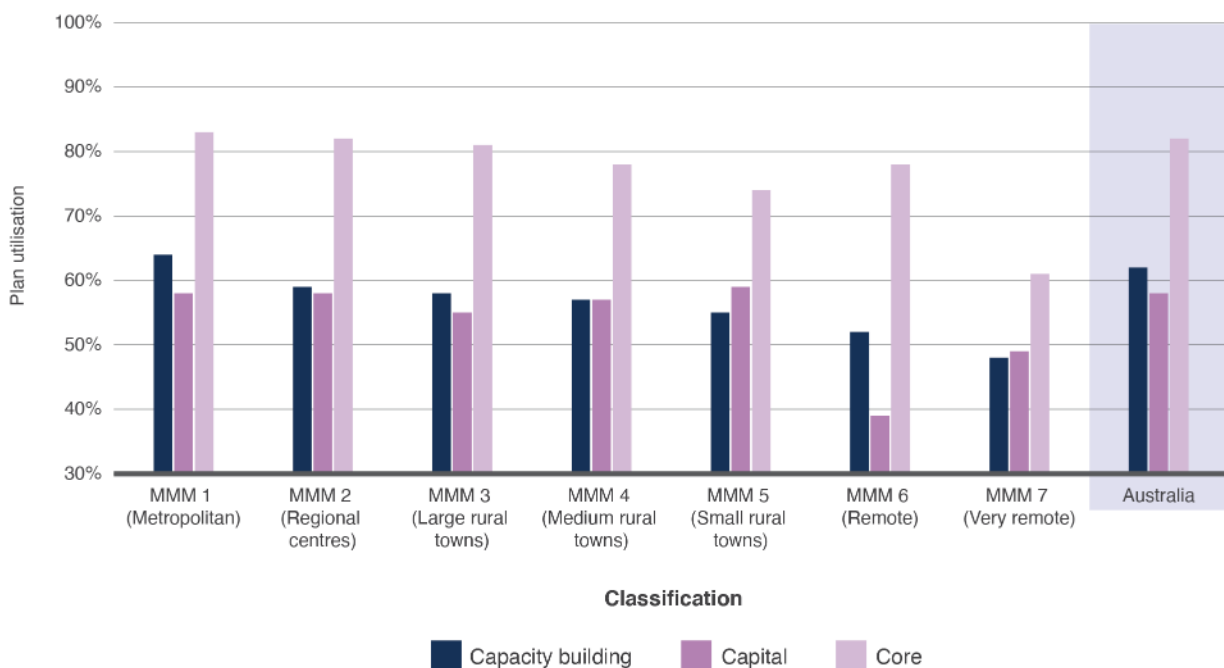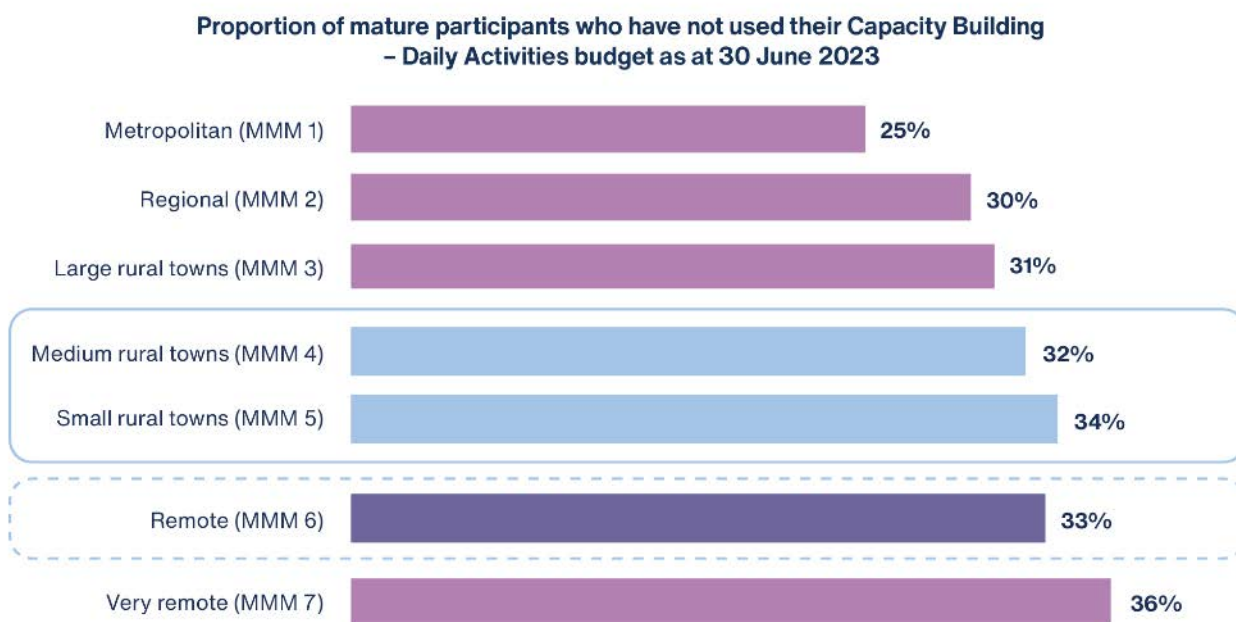
Figure 141: The proportion of mature participants who have not accessed their funded therapy supports in small to medium rural towns is similar to the proportion in remote communities.[1986]

Proportion of mature participants who have not used their Capacity Building – Daily Activities budget as at 30 June 2023

Region	%
Metropolitan (MMM 1)	25%
Regional (MMM 2)	30%
Large rural towns (MMM 3)	31%
Medium rural towns (MMM 4)	32%
Small rural towns (MMM 5)	34%
Remote (MMM 6)	33%
Very remote (MMM 7)	36%

Average utilisation of Core and Capacity Building budgets is lower in rural, remote and very remote parts of Australia, and utilisation of Capacity Building supports is consistently lower than Core supports. This is similarly the case for the proportion of mature participants – that is, participants who have been in the scheme for one or more years – who are not accessing therapy supports despite having the budget to do so.

Insufficient pooling of demand across multiple participants to attract providers has led to a lack of sufficient choice and often gaps in sustainable access to quality supports in rural areas

Participants may need to travel great distances by road, sea or air to access the supports and services they need. This can be very costly and unsustainable for many participants, particularly for allied health supports that need to be delivered regularly over time to build participant capability.

To date, the NDIA has tried to address thin market issues in rural and remote Australia using competitive approaches and pricing initiatives. Addressing market gaps in rural and remote Australia, however, will likely need more assistance from governments to coordinate demand in the market.

Box 76: How are 'market gaps' measured?

There is no one 'right' way of defining and measuring market gaps.

In its role in monitoring and stewarding NDIS markets, the Department of Social Services has measured market gaps by comparing the spread of participant utilisation by geographic location against the national median utilisation.

The national median utilisation looks at each participant's utilisation of supports across Australia, and taking the 50th percentile (or 'median'). This is used as a proxy measure of what 'good' utilisation looks like, and removes any outliers in plan utilisation.

Calculations of national median utilisation would:

- only include participants who have been in the scheme for at least two years. This definition is used to try to identify persistent market gaps as participants often need time to understand the scheme and how to use their budget, and to find suitable providers.
- allow for payments to be made 3 months after supports are delivered – that is, a '3 month lag'.

By location (such as remoteness, postcode or other geography), the market gap is then defined as:

- How much more participants who have utilisation below the national median would need to spend to bring their utilisation to the national median, divided by
- The total spend on specified supports in the location.

Market gaps still exist in metropolitan areas as participants' utilisation in metropolitan areas can be below the national median. For example, some of the participants who live in a metropolitan area may have difficulties accessing specific supports (like a psychologist). This may result in these participants' utilisation being below the national median.

Market gaps can be calculated for a specific group of supports, but excludes in-kind supports. Unless specified, market gaps would include all supports, excluding consumables, transport, assistive technology and home modifications supports budgets.

Figure 142: Market gaps by remoteness, from 1 July 2021 to 31 March 2022 and from 1 July 2022 to 31 March 2023[1987]
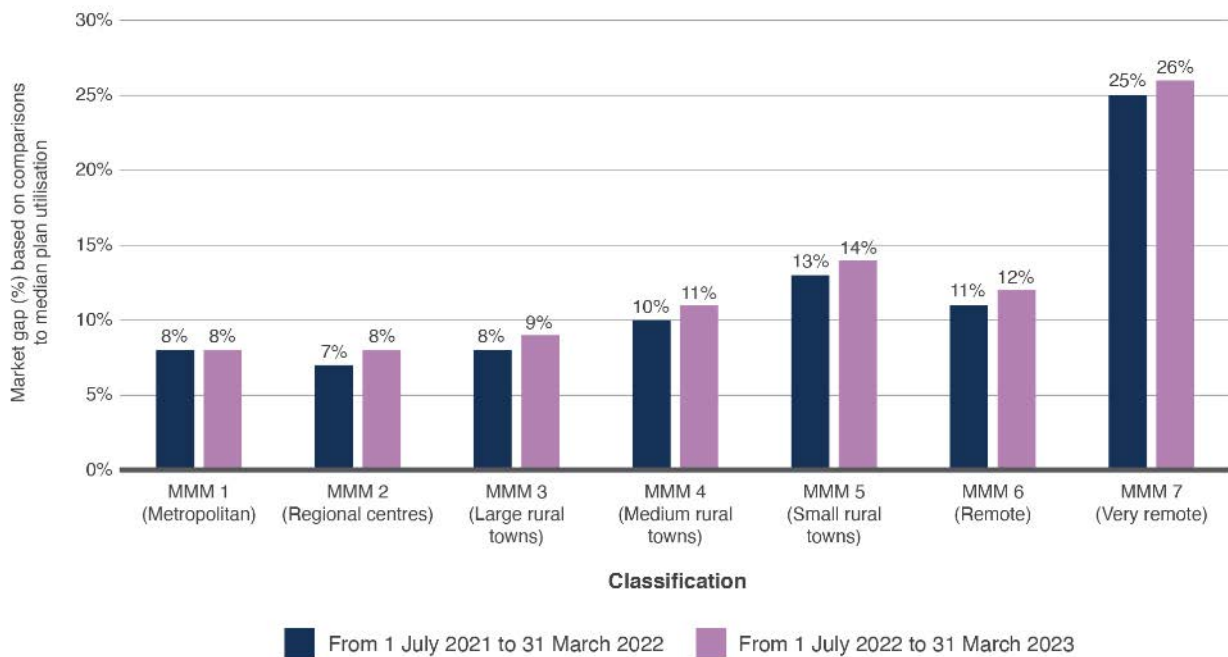
In the past few years, a number of pricing initiatives have been used to address thin market issues in these rural and remote areas. These include enabling flexible modes of service delivery (such as using telehealth), increasing allowances for provider travel, and increasing price limit loadings for remote.

Yet, the adequacy of allowances for provider travel to rural areas is still a concern by many providers.[1988] We have also heard concerns from participants and intermediaries about the impact these arrangements have for participant spend, particularly around allied health supports.[1989]

> *"Currently NDIA enables OTs to fund travel costs out of plan funded hours. This compensates OTs for lost practice time, but as this funding is taken out of a participant's total therapy support funded hours, it impacts the provision of capacity building therapy supports, which is important especially for participants with limited funding. It also disproportionately affects participants who are located in regional or rural locations where there are no or limited locally based OTs (particularly for participants requiring very specific supports due to complex or rare disability), and therefore OTs require longer travel time to access them." – Occupational Therapy Australia[1990]*

It is also worth noting that increases in price limit loadings for remote do not apply to many medium rural towns (MMM 4) and small rural towns (MMM 5). This is despite many of these communities facing similar challenges for supports and services to be delivered in those areas. Remote price limits have been recently extended to some of these communities which are

surrounded by remote areas.[1991] However, these still do not address the inherent market coordination challenges that arise from having individualising budgets and competitive approaches in these communities.

> *"If a provider needs to travel a distance, they should try and see other participants in the area too to share the cost." – Carer of NDIS participant & NDIS provider[1992]*

Participant-driven pooling of demand through current CFPs or new matching tools (see Action 13.3) go some way in creating market 'thickness' in rural areas, but these are unlikely to generate sufficient 'thickness' in rural and remote NDIS markets.

Specialised resources and dedicated focus are required to manage the process of initiating a CFP, analysing demand, developing the CFP and identifying and selecting possible providers. This would be inequitable for those participants in rural areas simply to be able to access needed services.

So although CFPs have shown some success, these (and similar) tools are unlikely to overcome the inherent market coordination issues in rural and remote areas, and tackling these issues is necessary to ensure continuity of supply for participants in these communities.

> *"Regional and remote areas have limited supports, limited safeguards and poorer quality supports. Market based systems do not work in thin markets." – Participant[1993]*

5.4.2 More coordination of demand is needed to deliver more sustainable access to allied health supports in parts of rural Australia

While market gaps are greatest in remote and very remote Australia, more holistic approaches that support longer term investment in the community is needed to address the unique, intersecting challenges in remote service delivery. These are discussed further in Section 6.

On the other hand, rural communities may have more existing infrastructure, capacity and capability which can be built upon. Addressing market gaps in these areas will need to identify and prioritise the greatest need and market gaps.

Across rural Australia, the proportion of mature participants who are not accessing therapy supports is highest in small rural towns (MMM 5). The proportion in small rural towns is even higher than in remote areas (MMM 6). Figure 143 similarly indicates that, outside of remote areas, the largest market gaps appear to be for capacity building supports in small rural towns (MMM 5). Similar market gaps also exist in medium rural towns (MMM 4).

Figure 143: In 2022-23, participants living outside of metropolitan and regional centres find it harder to access capacity building supports.[1994]

Remoteness	Classification	Market Gaps in Core supports	Market Gaps in Capacity Building supports
Metropolitan	MMM1	6%	15%
Regional centres	MMM2	5%	20%
Large rural towns	MMM3	6%	22%
Medium rural towns	MMM4	8%	23%
Small rural towns	MMM5	10%	24%
Remote communities	MMM6	8%	26%
Very remote communities	MMM7	20%	32%

Having a different approach for MMM 4 and 5 areas (medium and small towns) is in line with the Home Care Viability Supplement for in-home aged care, which applies a daily supplement for MMM 4-7 areas, but not MMM 1-3 areas.[1995] However, tackling supply gaps and challenges in delivering therapy supports to small and medium rural towns (MMM 4 to MMM 5) must acknowledge that the NDIS does not operate in a vacuum. Service recipients in other care and support sectors likely need similar services and face similar difficulties in accessing services and attracting supply due to low levels of demand and high costs.

There is clear potential for improving access to specific supports if demand across participants and other sectors is coordinated and packaged as a whole for potential providers.

In these communities, more contestable approaches are needed. Setting up provider panels would help lower the cost of service delivery by improving coordination of travel and improving providers' ability to share costs and resources. With increased certainty of demand, providers should be encouraged to invest in communities and build on existing community infrastructure, capacity or capability. These investments may be needed for providers to sustain service delivery in these areas in the longer term.

To improve access to specific supports, Australian Government agencies and state and territory governments should work collaboratively with local communities and existing service providers to assess demand for specific capacity building supports across multiple sectors. This could include aged care, childcare, education, foundational supports and specialist disability supports in rural communities. This would help identify the scale and nature of demand for capacity building supports to inform the setting up of comprehensive provider panel arrangements that can fulfil community need for capacity building supports.

"If a preferred provider model reduced participants' ability to access services outside of this list of providers, or introduced tiered pricing or conditional access requirements, then this would risk impacting client choice and control, which is a central tenet of the NDIS. … It is noted that in the areas of thin markets, especially in remote or regional areas, or areas that require additional training and support, for example delivery of services that are culturally safe for First Nations participants, then some form of preferred provider arrangement may be beneficial to enable commissioning of services for a group of participants." – Occupational Therapy Australia[1996]

Box 77: How could provider panels could be set up in small and medium rural towns

First, governments should work with the community to assess and understand the nature of allied health support needs and preferences, and providers already delivering supports to the community and where the service gaps exist. This should include:

- The nature and level of allied health supports which are needed by all people in the community, including: all people with disability, children and their families, older Australians and veterans
- Existing providers who are delivering allied health supports into the community, and how they are doing so, such as whether they are local, or travelling in and out of community
- Where allied health service gaps exist, for example, access to specific allied health services, more specialist services, or culturally safe and informed approaches.

Provider panels should then be set up based on the mix of allied health supports that are needed. Existing and prospective providers should then be encouraged to respond with their best service offering.

Providers should be selected to join the provider panel for limited periods of time. The criteria for choosing providers should include (but is not limited to): provider's performance (including feedback from community where they already deliver services in the community) and their capacity and capability to meet the community needs. In joining the panel, providers should be required to agree to the terms set out, which could potentially include specific service delivery approaches or performance measures.

Provider panels should be time-limited and re-tested at least every few years. This would provide governments with the ability to reassess suitability of providers based on their performance in meeting agreed service standards and delivering outcomes. It would also enable governments and communities to evaluate whether the panel is delivering outcomes and consider whether other approaches are needed.

Box 78: How provider panels could work for people in small and medium rural towns

Provider panels should offer participants (and other people in the community) more access to safe and quality allied health services from the group of providers.

Provider panel arrangements may specify that providers deliver supports in a specific way. This should encourage providers to collaborate and coordinate with each other on how they deliver supports to the community. For example, this could include:

- Panel providers coordinating travel into communities at regular intervals, rather than participants individually having to travel to an allied health provider or arrange their chosen allied health provider to travel into the rural community. Costs to the people in the community would be lower as costs for travel could be shared across providers and people in the community. Services could even be delivered more frequently.
- Panel providers could also use technology (such as telehealth and videoconferencing) where the community infrastructure supports this approach. A hub-spoke model could be used, where people receive supports from local allied health assistants and practitioners deliver supports with the supervision of more experienced or specialist allied health providers.

Providers who are delivering safe and quality supports should have more incentive to grow their footprint and invest in the local community's capacity and capability to sustain service delivery, since they would have greater assurance of demand and lowering costs of service delivery.

Yet, providers should not be able to be complacent either. Providers who are not delivering supports to the expected standard would either need to improve or they would be replaced by better quality providers. Determining whether providers are meeting agreed service standards or outcomes should take into account the experiences of people in the community in getting supports from the provider.

Although provider panels should start where the need and market gaps for specific supports are greatest – that is, capacity building supports in small and medium rural towns – they can also be used flexibly in other areas where supply gaps persist.

> *"The problem with 'choice and control' when you live in a rural area is that you may only have one choice of provider. I am trying to get my wheelchair repaired. I have been battling for 2 years to get this done. I rely on my chair to live independently and work… I was told by a provider that they would take my chair off me for 12-18 months to fix it and it was 'not their problem' that I would have no wheelchair."*
> *– Participant[1997]*

5.4.3 Action & Implementation Details

Action 13.2: The <u>National Disability Insurance Agency</u> should progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps

Provider panels should leverage good providers already operating in these areas and be retested at least every three years (or earlier where the panel is not meeting agreed service standards and outcomes). This would ensure panels are lowering the cost of service delivery through greater coordination of travel and sharing costs and resources among providers, and increasing certainty of demand for providers to encourage investment in communities.

Provider panels should be progressively rolled-out in small- and medium-sized rural towns (Modified Monash Model categories 4 and 5), and used flexibly in other areas where supply gaps persist. Initial pilots should be evaluated to ensure settings are fit for-purpose ahead of any wider roll-out of panels.

Implementation detail:

- Provider panels are an important way of enabling participants to access quality supports and have control and choice, where it does not exist today or exists in name only. When establishing these provider panels, the National Disability Insurance Agency, in consultation with other Australian Government and state and territory government agencies, should:

  - pay providers in line with the pricing arrangements and price limits set by Independent Health and Aged Care Pricing Authority (see Recommendation 11). In instances where there are exceptionally high delivery costs, flexibility should be used to pay providers above the price cap.

  - limit extensions to how long these arrangements are in place without being re-tested. Where providers are unable to achieve economies of scale in the long term, other contestable approaches, including alternative commissioning (see Recommendation 14) or provider of last resort arrangements (see Action 13.4), should be considered.

5.5. Governments are responsible for ensuring participants have continued access to critical supports when markets fail

Even when using market-driven service delivery approaches, governments (as market stewards) retain responsibility for ensuring participants are not left without critical supports.

It is not, and should not be, the role of the scheme to support failing providers. But governments should ensure that supports for participants are provided in the most effective and efficient way.

Governments also have a responsibility to ensure continuity of support and access to supports needed to protect the wellbeing of participants.[1998]

The Disability Royal Commission, however, highlighted that the NDIS has led to a "… situation in which there is no clearly identified, or identifiable, provider of last resort for a person with disability, including for people who are homeless or at risk of homelessness".[1999]

Participants may be left without supports and services they need when providers exit the NDIS market, other service disruptions occur or when providers fail to enter the market to provide supports. In some cases, participants may face dire consequences without access to supports and services that are critical to their health and wellbeing, putting pressure on other support systems including hospitals.

> *"Because of the remoteness, lack of infrastructure and high costs of service delivery, there are often very few service providers, apart from some government services in remote communities. In terms of disability services there are few, if any, allied health specialists, equipment retailers or repairers, and minimal personal care and respite options. There is virtually no choice in providers and no provider of last resort when there is a crisis." – Submission from Machado-Joseph Disease (MJD) Foundation to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability[2000]*

5.5.1   Policies and processes around provider and market failure are opaque

> *"A market approach to disability services has not worked for everyone. Urgent discussions are required between governments to develop provider of last resort schemes to meet the needs of people with disability unable to access adequate or appropriate disability supports." – Disability Royal Commission[2001]*

There is a lack of transparent policies and processes to detect and escalate concerns around different scenarios when NDIS markets are unable to deliver critical supports to participants (see Section 5.1). These scenarios could include when providers suddenly withdraw services, providers are unable to deliver supports during disasters or emergencies, or providers fail to enter into markets.

The NDIA has a *Maintaining Critical Supports Framework* and supporting *Provider Exit Framework* but this is not available publicly. This is despite calls from both the Productivity Commission and Joint Standing Committee to publish these documents.[2002]

We have heard that with no visibility of these policies and processes, participants, their decision-supporters and providers have little to no confidence that they will be supported when there are sudden exits or withdrawals of services.

> *"Government needs to be a Provider of last resort for participants with complex needs. The market system does not work well for participants with complex needs, particularly in rural/ regional areas." – Anonymous[2003]*

"However, in the absence of a 'provider of last resort', further information is needed about how the NDIA will respond in situations where the wellbeing of a participant is at significant risk due to the person not being able to access necessary supports or services. To address this, the NDIA should adopt and publicise a clear policy on the provision of services to NDIS participants who may be at risk due to the disability services market's inability to meet the participant's service entitlements. The NDIA should adopt and publicise a clear policy and associated guidelines surrounding the provision of services to any NDIS participant whose wellbeing is at significant risk due to the disability services market's inability to meet the participant's service entitlements." – Dr John Chesterman, Public Advocate for Queensland[2004]

With limited data collected on when providers exit or withdraw services, it is also difficult to evaluate how effective the current policies and processes are in supporting participants in the event their provider exits an NDIS market or withdraws services (see Section 5.1).

There are no clear roles and responsibilities of governments in addressing market failure. For participants with more complex needs, this often means they may be exposed to greater risk of going without critical supports for long periods of time.

"Identifying how the NDIS Commission and the NDIA can better share data related to individual participant risks as well as the risks that market failure and thin markets present, would also strengthen participant safeguarding." – National Disability Services[2005]

5.5.2 Provider of last resort arrangements are needed to give participants confidence that they will continue to get the supports they need when markets fail

Transparent provider of last resort policies and processes are needed for governments to identify, implement and be accountable for appropriate and timely responses to failures in NDIS markets. The policy should outline:

- how the NDIA will proactively monitor the market and detect potential risks of provider exits and market failure
- how governments, participants and providers can raise and escalate concerns of provider exits and market failure
- how various levels of governments will work together to ensure participants are not left without critical supports.

In developing these arrangements, governments should consider what market access arrangements should be in place when participants are unable to find a provider to deliver the supports they need, particularly where:

- participants face unacceptable or immediate risks of harm either to themselves or the people around them without these supports; or

- participants have complex needs and are required to navigate multiple service systems to get supports in place.

Provider of last resort arrangements should also ensure service delivery is at arm's length from the commissioning body and that providers meet relevant safeguarding and quality standards. Where appropriate, these arrangements should be set up to leverage existing infrastructure and established service delivery systems in other sectors.

5.5.3   Action & Implementation Details

Action 13.4: All Australian governments through the Disability Reform Ministerial Council should agree and publish a provider of last resort policy to ensure participants have continued access to supports where markets fail

Provider of last resort arrangements should be evidence-driven and underpinned by market monitoring (see Action 13.1). They should be reviewed every five years to ensure governments' market responses remain timely, effective and fit for-purpose.

These arrangements should be part of a broader approach in how governments maintain access to critical supports for participants, including where services cannot be delivered as a result of natural disasters.

Implementation detail:

- The National Disability Insurance Agency and new National Disability Supports Quality and Safeguards Commission should publish policies and procedures on how they maintain critical supports for participants in different scenarios. This would include any policies and procedures when:

  - providers decide to exit the market or cease delivering certain NDIS supports. This includes when potential exits or service withdrawals leave participants without suitable alternatives that deliver the quality or standard of supports they require to be safe.

  - participants are unable to access certain supports and services when natural disasters or other unforeseen events occur.

  - individual participants experience unforeseen crises or sudden and significant changes in circumstances.

- The Australian Government and state and territory governments should agree on provider of last resort arrangements including the:

  - conditions when specific supports would be delivered using provider panel arrangements (see Action 13.2), alternative commissioning approaches (see Recommendation 14), or where governments would directly provide supports

- circumstances (if any) where governments may provide assistance to providers in NDIS markers where there is a risk of future supply gaps for participants (for example, this could consider the risk of sudden market failure should an at-risk provider fail)

- roles and responsibilities for governments, Navigators and providers.

- As recommended by the Productivity Commission in 2017, the National Disability Insurance Agency should also collect and regularly publish disaggregated data on when provider of last resort arrangements are used.

6. Access to supports for First Nations communities and all participants in remote communities

- Improving outcomes for First Nations participants requires equitable, accessible, culturally informed NDIS supports that take into account the strengths of First Nations communities, their rights as Indigenous peoples and concepts of disability, care and kin. Yet, across Australia, First Nations participants have limited access to culturally appropriate supports. Only 38 of 145 National Aboriginal Community Controlled Health Organisation (NACCHO) members are providing supports as registered NDIS providers. Little data is captured on other Aboriginal Community Controlled Organisations (ACCOs) who may be delivering NDIS supports and services.

- While increases in remote and very remote price loadings and more flexible pricing arrangements to cover telehealth have addressed some challenges in remote service delivery, persistent market gaps remain. In remote and very remote Australia, around two in five participants who have been in the NDIS for over one year are not accessing daily activity supports, and over one in three are not accessing therapy supports. It can be even more difficult for participants to access culturally safe supports in some of these communities.

- Addressing market gaps for remote communities and in First Nations communities will require a different market approach that can better coordinate supports. When placed-based and community-driven, alternative commissioning could help the NDIS to deliver more culturally informed, equitable and sustainable supports for both First Nations communities and remote communities. These approaches could also build on the strengths of local communities, improve outcomes for participants and drive a more sustainable care and support ecosystem over time.

- Ongoing, meaningful and on-the-ground partnerships with First Nations representatives, communities and participants will be key to success. The National Agreement on Closing the Gap, its Priority Reforms and the Disability Sector Strengthening Plan offer a framework to progress alternative commissioning in genuine partnership with the First Nations people with disability, families, communities and organisations.

- Expanding too far, too fast is a significant risk. Time is needed to build community trust, commission capability and roll out alternative commissioning approaches across both remote and First Nations communities. This should be done on a community by community basis.
- Piloting approaches will help to understand what works and allow time to develop and strengthen community partnerships. Over time, communities should be supported to buy and coordinate supports for themselves. Where there is effective local governance and they wish to, communities could design the approach and lead the commissioning process.

Recommendation 14: Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements

- Action 14.1: The <u>National Disability Insurance Agency</u>, in partnership with <u>First Nations representatives, communities, participants and relevant government agencies</u> should progressively roll-out alternative commissioning arrangements for both First Nations communities and remote communities, starting as soon as possible.

6.1. Opportunities for more culturally appropriate and sustainable services in First Nations communities and remote communities

6.1.1 Current approaches to delivering NDIS supports are persistently failing to meet the needs of First Nations communities across Australia as well as participants in remote communities

Evidence from past and ongoing reviews and inquiries[2006] continues to show that the current competitive market-based model with individualised funding arrangements persistently fail to understand and meet the needs of both First Nations communities and remote communities.

> *"Whilst there are thin markets and gaps in available disability services and supports in all locations that are culturally inclusive and safe, there are additional thin market challenges in rural, remote, very remote locations. For example, cost, existence of community-controlled organisations already delivering a range of services with different reporting, regulatory and governance requirements, workforce, and appropriate infrastructure. This exists for both NDIS and non-NDIS related service delivery." – Closing the Gap Disability Sector Strengthening Plan 2022[2007]*

The NDIS has gone some way to improving equity in access to supports for First Nations people with disability. As at 30 June 2023, 7.6 per cent of NDIS participants identify as First Nations participants, with 68 per cent of First Nations participants in remote and very remote communities receiving disability supports for the first time.[2008]

However, First Nations participants and participants living in remote communities still face persistent challenges in accessing NDIS supports.

This is representative of broader systemic issues impacting equity of support for intersectional populations but is exacerbated within the NDIS as the scheme struggles to understand and respond to cultural rights, needs and ways of being.

> *"We have received inconsistent advice on whether 'return to country' for short visits to connect with family, or participate in ceremony, is funded under the NDIS as some planners have considered those visits as a holiday rather than a cultural, necessary and reasonable support requirement." – Somerville Community Services[2009]*

Improving outcomes for First Nations participants requires equitable, accessible, culturally informed NDIS supports that take into account the strengths of First Nations communities, their rights as Indigenous peoples and concepts of disability, care and kin.

> *"My Aboriginal Workers have empowered and made me feel safe again." - NDIS Participant[2010]*

> *"It is important to have Aboriginal workers who understand culture, my family and my community. Trust is so important and they help us to talk to mainstream providers." Carer of NDIS Participant[2011]*

A historic lack of services within remote communities pre-dates the NDIS and has led to limited or no knowledge and understanding of disability supports.[2012] In remote communities, the increased demand for services driven by the NDIS has often not been met with an increase in services.[2013]

6.1.2 Very few alternative commissioning approaches have been trialled for First Nations communities across Australia and for participants in remote communities

Past reviews and inquiries have repeatedly called for alternative commissioning approaches to be explored where market approaches are failing, particularly for remote and very remote communities (Figure 144).

Figure 144: Numerous past reviews and inquiries recommended alternative funding and alternative commissioning approaches, particularly for remote and very remote communities

Numerous past reviews and inquiries recommended alternative funding and alternative commissioning approaches, particularly for remote and very remote communities

2017

Productivity Commission report on NDIS Costs suggested a more tailored response to a wide variety of thin markets could include:

- More collaboration, coordination and integration of services
- Use of community or place-based services
- Partial or full block funding to commission or procure services

Joint Standing Committee on the NDIS Inquiry into Transitional Arrangements for the NDIS heard "alternative funding models, including fixed or block funding must be made available in areas of thin and failing markets"

NDIA & DSS commenced work to develop the **NDIS Thin Market Approach**

2018

Joint Standing Committee on the NDIS recommended trialling alternatives to a fee-for-service delivery model to address thin markets in rural and remote areas

2019

NDIS Thin Markets Framework developed. Recommended very remote communities need alternative commissioning approaches

Tune Review recommended changes to give NDIA more defined powers to undertake market intervention, particularly to explore alternative commissioning approaches in "remote areas where market supply is thin or absent"

Disability Reform Council committed to using a more flexible approach to NDIS thin markets

NDIS Thin Market Trials commenced

2020

Thin Market Trials (as at December 2022): 39 trials across Australia with:

o **6 completed** in remote or very remote

o **15 currently underway** in remote or very remote areas, including 1 direct commissioning project

o **7 completed** trials and **11 still** underway in non-remote

2021

2022

Queensland Productivity Commission Inquiry on the NDIS Market in Queensland recommended that "alternative commissioning models for purchasing supports [should be considered] where other market-oriented options are not viable"

Yet, despite these calls, only three of the 39 NDIS thin market trials have explored alternative commissioning approaches (see Section 5.2.3). All three trials explored a direct commissioning approach for a narrow selection of supports, and only one of these was undertaken in a remote context.

Box 80: What is "commissioning"?

> **Commissioning** is a process of purchasing supports or services from a provider or group of providers. The commissioning process could involve agreeing what supports and services are delivered, as well as how much would be paid for delivering the support or service.
>
> **Alternative commissioning** refers to different commissioning approaches (Figure 145) that can be used to purchase supports or services for a group or community of people (including participants). Governments typically commission supports or services, but communities can also commission supports or services.

Figure 145: Types of alternative commissioning arrangements

There are different alternative commissioning arrangement approaches

Direct commissioning

Direct commissioning is where supports are directly purchased on behalf of a group of participants. Supports can be purchased from non-government or government providers – who should ideally be separate from the funding body to ensure a level playing field.

Integrated commissioning

Integrated commissioning involves selecting a provider to provide supports across multiple service types for a defined area. What supports and services are commissioned and how they are delivered is based on identified community needs.

Community commissioning

Community commissioning is where communities are empowered, or use cooperative approaches, to lead the commissioning process. Communities, rather than governments, determine the services and providers that best meet their needs. Community commissioning may be implemented using direct or integrated commissioning.

In the one remote trial, it is unclear if increases in spending reflected an increase in participant use of supports (see Section 5.2.3). The Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Women's Council noted parts of the community were unclear about how the NDIA captures, monitors and responds to feedback on how well the directly commissioned service is working for participants in the community.[2014] This included feedback about how culturally safe and appropriate the supports are.

Importantly, the evaluation of the thin market trials did not follow best practice Indigenous evaluation approaches.[2015] The lack of First Nations voices in the evaluation makes it difficult to

make any robust conclusions, and learn from what has or has not worked for these First Nations communities across metropolitan, regional, rural and remote Australia.

6.1.3 Community-driven alternative commissioning approaches can strengthen the community-controlled disability sector

Complex and confusing NDIS policies and processes have made it difficult for First Nations people with disability to access and navigate the NDIS. The relatively low number of First Nations participants with a plan and the cultural appropriateness of planning processes were among the many concerns raised during the 2020 Joint Standing Committee Inquiry into NDIS Planning.

Compared to non-Indigenous participants, First Nations participants have higher value plans. Lower levels of plan utilisation arise from lower levels of spending.[2016]

> *"…while demand is growing for First Nations disability services, First Nations NDIS participants are 28% less likely to receive care via the NDIS than their non-Indigenous counterparts. The research finds some of these disability services could be described as 'unsafe, traumatising and inequitable." – Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability [2017]*

Limited availability of accessible, culturally appropriate care and supports may mean First Nations participants need to choose between getting culturally unsafe supports, and not getting funded supports at all.

> *"Aboriginal people will only access those services where they feel culturally safe and prefer to use Aboriginal community-controlled health services when available."*
> *– Aboriginal Health Council of South Australia Ltd (AHCSA) [2018]*

> *"Sometimes if my workers is not available I go without support but not for very long. It is important to me having Aboriginal staff I trust support me." – NDIS Participant[2019]*

> *"We are yet to see a tailored Aboriginal NDIS services that [meet] our needs in a culturally safe manner. …In our communities we see Sole Providers, coerce and take advantage of our vulnerable peoples. Reap the rewards/ funds of their plans, leaving our people with nothing and with no outcomes." – Carer of person with disability[2020]*

First Nations community-controlled organisations may be reluctant to deliver NDIS services. Individualised funding packages can provide uncertain funding for community-controlled organisations, limiting their ability to build trust within the communities they are supporting. This uncertainty can also limit their ability to invest in longer term staffing contracts. These organisations also typically do not have significant financial reserves or experience operating in a fee-for-service market.

Figure 146: Between September 2022 and August 2023, a small number – including just 38 of 145 NACCHO members – provided supports as registered NDIS providers[2021]

Available data shows that there are no NACCHO members based in Victoria, Tasmania or the ACT who have delivered NDIS supports as registered providers.

Other First Nations organisations and other NACCHO members may be delivering NDIS supports in these and other areas across Australia.
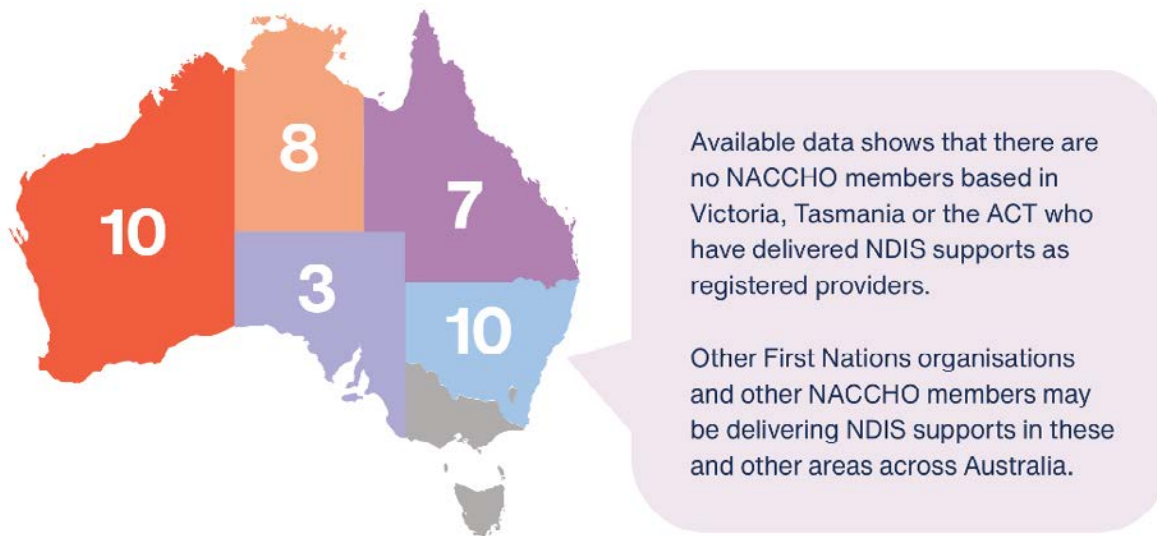
Note: Data only includes organisations who are members of NACCHO who are registered NDIS providers or have been paid for delivering NDIS supports between 1 September 2022 and 31 August 2023. NDIS data captures limited information on Aboriginal Community Controlled Organisations (ACCOs) who may be delivering NDIS supports and services.

> *"There is no way to understand how many registered or unregistered NDIS providers Aboriginal and Torres Strait Islander are owned or staffed." – Community Services Industry Alliance [2022]*

The capacity of First Nations communities – which include First Nations people with disability, their family and kin, community, and provider organisations – to drive and develop culturally appropriate care and supports is also being hindered in the current approach.

Figure 147: Market-based model with individualised funding arrangements works against First Nations community-led decision-making and initiatives[2023]

"... while individualised NDIS funding allows tailoring of services to individual need and choice, it does however, stifle the opportunity to create an innovative response to community need or to strengthen local workforce capacity accordingly. In this way, **individualised funding alone, can work against Aboriginal concepts of holistic health and wellbeing for the whole community.**"

– Barker et al. 2021

"The Coalition of Peaks Disability Sector Mapping Report (2021) identified that the several jurisdictions considered the market-based nature of the **NDIS funding model impacts client relationships as it does not allow for community relationship building and storytelling / information gathering to ensure informed decision making for First Nations people with disability.**"

– Disability Sector Strengthening Plan

"The guts of the problem is that, ultimately we want Aboriginal-led care. We will never know the cultural protocols for each language group across Australia. Then the Western Way of Being is INDIVIDUAL COMPETITIVE AND HIERARCHICAL, leading to funding and care models based on the individual person. Whereas Aboriginal ways of being is COLLECTIVE, COLLABORATIVE AND CIRCULAR, this leads to funding and care models that reflect this" – Quote from Psychologist from Australian Association of Psychologists Inc [2024]

A number of ongoing initiatives are aimed at ensuring the NDIS is more culturally safe and responsive for First Nations people to access and navigate the NDIS (see Box 81). However, more needs to be done to address the systemic issues impacting equity in the scheme and to provide accountability for the successful implementation and evaluation of existing and new initiatives (see Actions 2.10 and 20.4).

Building the cultural competency of existing NDIS providers will go some way to strengthening the responsiveness, quality, and range of services delivered to First Nations people with disability.[2025]

However, priority should be to strengthen the community-controlled disability sector. Building First Nations community-controlled sectors is one of four Priority Reform areas under the *National Agreement on Closing the Gap* (*2020*). The disability sector is one of four initial sectors identified for joint national strengthening effort.

The *2022 Disability Sector Strengthening Plan (*Disability SSP*)* outlines six key areas for action to build the capacity of existing and new community-controlled disability services to deliver a full range of culturally safe and inclusive services. Key actions include localised community-led strategies, joined up service delivery and strengthening a dedicated First Nations disability workforce that embeds a cultural model of inclusion.

Investment in strengthening community-controlled disability services for all First Nations people with disability is also a priority for First Nations disability sector stakeholders.

First Peoples Disability Network's "National Disability Footprint" and "Ten priorities to address disability inequity" are both underpinned by building the capacity of First Nations' community-controlled organisations and growing the First Nations disability workforce.

Using alternative commissioning approaches, First Nations communities could commission community-controlled organisations to ensure the availability of disability supports that are responsive to their needs, particularly where the market has failed to respond.

In this way, community-driven alternative commissioning approaches can be a powerful tool to deliver culturally appropriate supports across metropolitan, rural and remote Australia.

There is also an opportunity through alternative commissioning in these remote communities to create sustainable jobs, train a new workforce and contribute to increased economic participation, which is a key goal of Closing the Gap.

Box 81: Initiatives to improve First Nations participant experience

The NDIA is currently working to build the cultural competency of NDIA staff and NDIA Partners through cultural awareness training. It is also embedding dedicated Aboriginal Disability Liaison Officers to support NDIA Partners deliver a more culturally inclusive and responsive participant experience.

Across some remote areas, the NDIA has also rolled out the following elements based on each community's needs and attributes:

- *Remote Community Connectors (RCC)* provide culturally appropriate and locally based support in remote areas, with a focus on improving First Nations peoples' awareness and understanding of the NDIS.
- *First Nations cultural brokers* have also been engaged in a limited number of locations to act as a conduit between the NDIA and remote First Nations communities.[2026]
- *Evidence, Access and Coordination of Planning Program (EACP)* help people with disability and developmental delay in remote communities to test their eligibility to access the NDIS and navigate the access process. This includes helping people with gathering evidence from mainstream services when applying to access the NDIS.
- *Remote Early Childhood Services (RECS)* pilot program to help children aged under 7 years access early supports and services. This is currently being piloted in Western Australia.

Kimberley Aboriginal Medical Services (KAMS) and its consortium members have been influential in the design, development, and implementation of the RECS program across Western Australia, including the Kimberley. This includes how this program intersects and complements the RCC and EACP programs.[2027]

In 2023, the NDIA has also established a First Nations Advisory Council (FNAC) which is jointly chaired by the CEO of First Peoples Disability Network and the CEO of the NDIA. The NDIA have committed to co-designing a new First Nations Strategy and action plan to improve the experience and outcomes for First Nations people with disability. This will be done in formal partnership with the First Peoples Disability Network (FPDN) and guided by the First Nations Advisory Council (FNAC).[2028]

The NDIS Commission has also funded some grants to remove barriers for Aboriginal Community Controlled Organisations (ACCOs) and enhance provider capability to deliver services to First Nations people living in rural and remote communities.[2029]

Under the Disability SSP, FPDN and Western Sydney University are currently developing a *Cultural Model of Inclusion Framework and Organisational Assessment Tool*. This framework and assessment tool aim to improve the quality of NDIS services to be culturally safe, inclusive and disability rights informed not just for First Nations participants. It is also designed to assist the NDIA when meeting the needs of participants from all culturally and linguistically diverse communities.[2030]

6.1.4 Place-based and community-driven alternative commissioning approaches can generate more responsive and sustainable supply in remote areas

Challenges in delivering services to remote areas are well-known. These are not unique to the NDIS, but they are amplified by the current competitive market-based model with individualised funding arrangements and gaps in market monitoring and scheme integrity mechanisms.
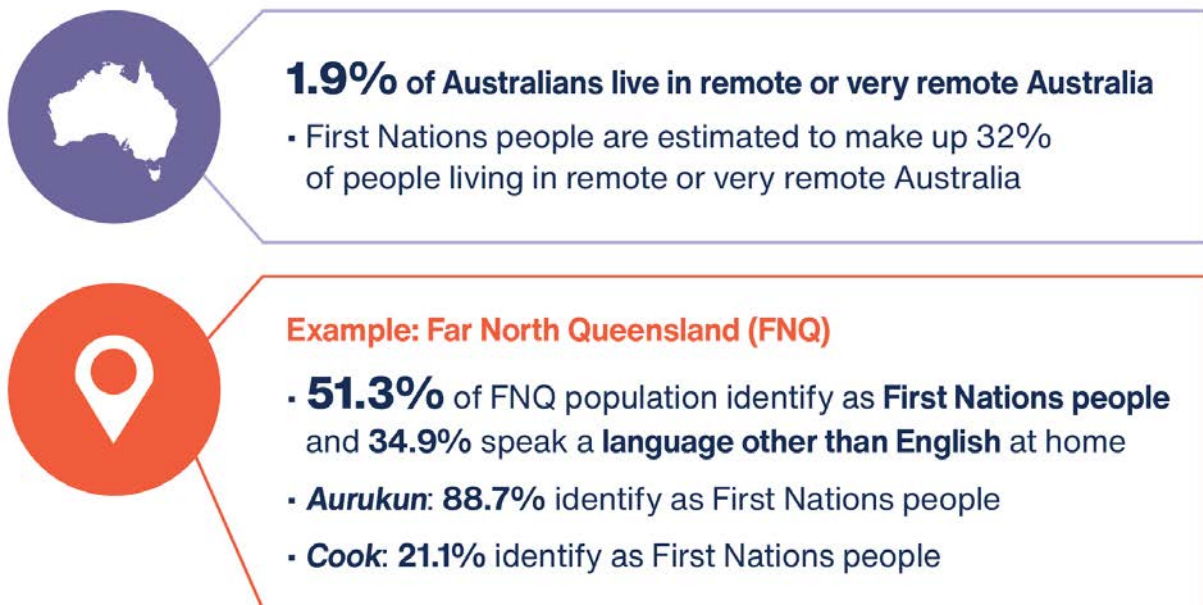
- **Demand is often low, geographically dispersed and fragmented** across government and non-government systems in remote areas.[2031]
- Individualised funding arrangements **further fragment an already low, dispersed demand for services**. They also increase demand risk, where actual demand for services is lower than the forecasted demand, since service providers are more exposed to changes in demand when a participant's NDIS funding is reassessed.[2032]
- **Service delivery costs are inherently higher in remote and very remote Australia**.[2033] These costs, such as investment for capital infrastructure and travel for fly-in, fly-out (FIFO) and drive-in, drive-out (DIDO) arrangements, particularly impact providers' financial viability since, under a market-based approach, these costs are often not shared across service providers.[2034]
- Service providers also face **more pronounced logistical difficulties and more acute workforce challenges** in delivering services to remote Australia.[2035]
- Prospective local providers are **reluctant to register as NDIS providers due to the regulatory impost and cost**.[2036] Existing First Nations community-controlled organisations are also reluctant to deliver NDIS services due to the financial risks involved and potential reputational risk with the broader community.[2037]

No one-size-fits-all approach to delivering NDIS supports will work for remote communities.

Each remote community has unique geographical considerations, demographic compositions and cultural contexts. For First Nations communities, connection to land, community, culture and kin also cannot be underestimated, particularly in remote Australia.

> *"Social and emotional wellbeing is the foundation of physical and mental health for Indigenous Australians. It is a holistic concept that encompasses the importance of connection to land, culture, spirituality and ancestry, and how these affect the wellbeing of the individual and the community." – Australian Institute of Health and Welfare* [2038]

Figure 148: Remote and very remote communities have fundamentally different cultural contexts, and they vary widely[2039]

1.9% of Australians live in remote or very remote Australia
- First Nations people are estimated to make up 32% of people living in remote or very remote Australia

Example: Far North Queensland (FNQ)
- **51.3%** of FNQ population identify as **First Nations people** and **34.9%** speak a **language other than English** at home
- *Aurukun*: **88.7%** identify as First Nations people
- *Cook*: **21.1%** identify as First Nations people

Pricing initiatives to date go some way in addressing these challenges

Price limits for NDIS supports have been adjusted in recognition of the costs associated with delivering supports to remote areas.[2040]

In July 2019, remote and very remote loadings were uniformly increased from 20 per cent and 25 per cent to 40 per cent and 50 per cent respectively.[2041] From 2020 onwards, the NDIA also introduced more flexible pricing arrangements allowing for services to be delivered via other models, including via telehealth.

This has seen some improvements in access to supports. Average NDIS plan utilisation rates increased in remote areas – from 58 per cent as at 30 June 2019 to 69 per cent as at 30 June 2023. Very remote areas have seen a larger change – increasing from 36 per cent as at 30 June 2019 to 55 per cent as at 30 June 2023.

Even so, participant outcomes in remote and very remote communities still lag well behind metropolitan and regional areas, which had average plan utilisation rates of over 75 per cent in June 2023.

Figure 149: Uniform increases in remote and very remote loadings in NDIS price limits are not enough to address thin markets in remote and very remote areas [2042]

Classification	Price Limit 1 July 2018	Price Limit 1 July 2022	Nominal increases in price (%), including loading	Utilisation as at 30 June 2019	Utilisation as at 30 June 2023	Change (%) in utilisation
MMM 1	$49.02	$62.17	26.83%	67%	77%	10%
MMM 2	$49.02	$62.17	26.83%	68%	75%	7%
MMM 3	$49.02	$62.17	26.83%	67%	74%	7%
MMM 4	$49.02	$62.17	26.83%	65%	72%	7%
MMM 5	$49.02	$62.17	26.83%	58%	67%	9%
MMM 6	$58.60	$87.04	48.53%	58%	69%	11%
MMM 7	$60.99	$93.26	52.91%	36%	55%	19%

However, market gaps persist in remote and very remote communities.

Applying a market-based approach to deliver high quality supports to, and outcomes for, NDIS participants in remote and very remote communities is not working.

Persistent market gaps remain through many remote and very remote communities. As at 30 June 2023, recorded market gaps were around 12 per cent for remote participants and 26 per cent for very remote participants (as defined in Section 5.4.1).[2043] These figures can conceal the severity of market gaps across remote Australia, with a number of locations experiencing market gaps of over 40 per cent during the first three quarters of 2022-23. In fact, across remote and very remote communities, over two in five mature participants – participants who have been in the NDIS for one or more years – are not accessing daily activity supports, and over one in three are not accessing therapy supports that assist with building skills and independence.

In remote and very remote areas, the severity of market gaps may mean some participants could be trading off their ability to remain in their community against accessing the supports they need. Often there is a greater need for local, culturally safe supports to be delivered to First Nations participants in remote areas, but First Nations organisations can be reluctant to become NDIS providers due to the regulatory impost and reputational risks involved.

> *"Many [First Nations] people were born in remote communities and due to their high level support needs had no other option but to relocate to urban areas to access essential supports." – Somerville Community Services[2044]*

In some cases, we have heard that people with disability living in remote communities are choosing to exit the scheme to access supports through the aged care system instead.[2045] For example,

where there is an aged care provider in their communities, it may be easier to get support for activities of daily living such as meals, showers and home cleaning from the aged care provider rather than finding one or more NDIS providers who can deliver these supports. In doing so, they are then losing access to other NDIS supports, such as assistive technology.

Figure 150: Remote and very remote Australia have greater share, severity and persistence in NDIS market gaps during 1 July 2022 to 31 March 2023[2046]
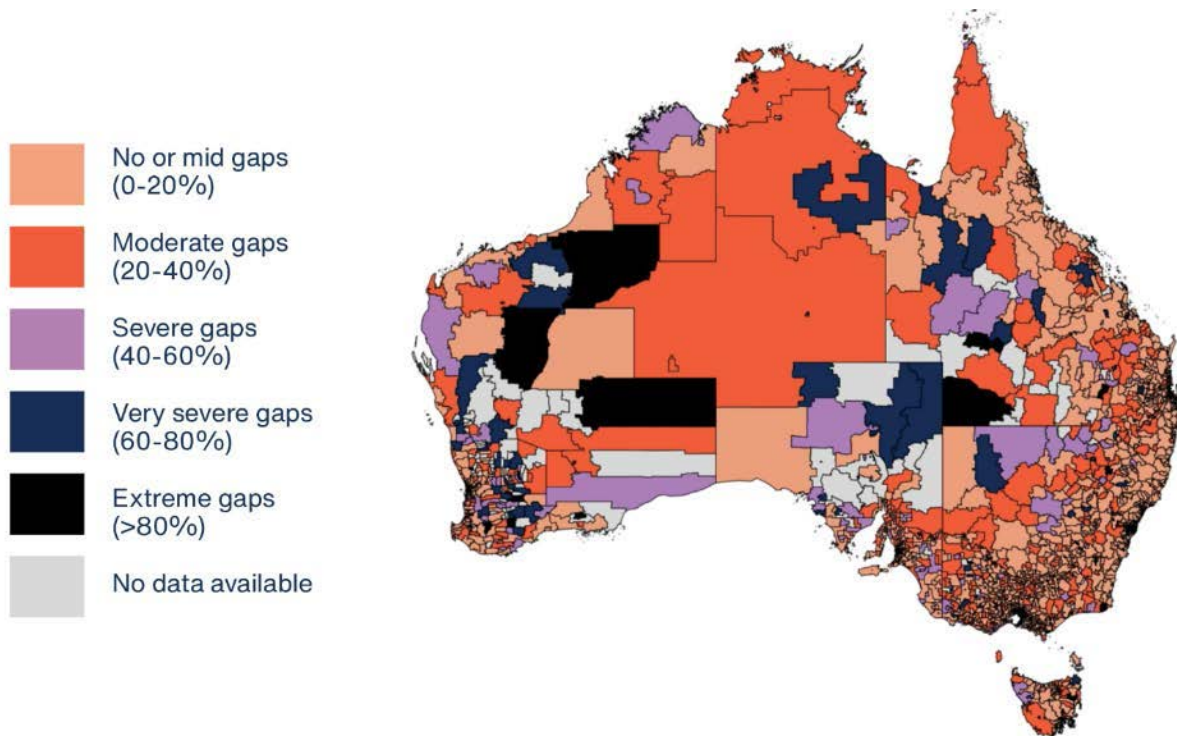
Even where participants are getting services, many of these services rely heavily on FIFO and DIDO arrangements rather than local, on-the-ground solutions.

> *"...there is a reliance on fly-in fly-out (FIFO) and drive-in drive out (DIDO) arrangements to provide services in these communities. This is very expensive, represents little value for money, and may also not be the best for the participants." –
> NACCHO 2021[2047]*

> *"The FIFO model does not work in these [remote] locations as the supports are irregular and inconsistent, resulting in participants being confused and without supports... The FIFO [allied health] services prioritises their availability and circumstances before the requirements/needs of the participant e.g. gap between provider travel and how this hinders therapy effectiveness (participant receives less therapy sessions)." – Xtremecare Australia Healthcare Services[2048]*

Where they are concerned about the safety and quality of available services (including cultural safety), participants often have little recourse to find safer or better quality services due to low market competition in these communities.

While it may increase market concentration in these communities, moving to place-based and community-driven alternative commissioning approaches can offer opportunities to create more holistic and sustainable services that are delivered where people live and by more local people. In this way, it can also create more job opportunities in remote communities.

Figure 151: During 2022-23, NDIS markets for core supports and capacity building supports is much more concentrated compared to non-remote areas [2049]
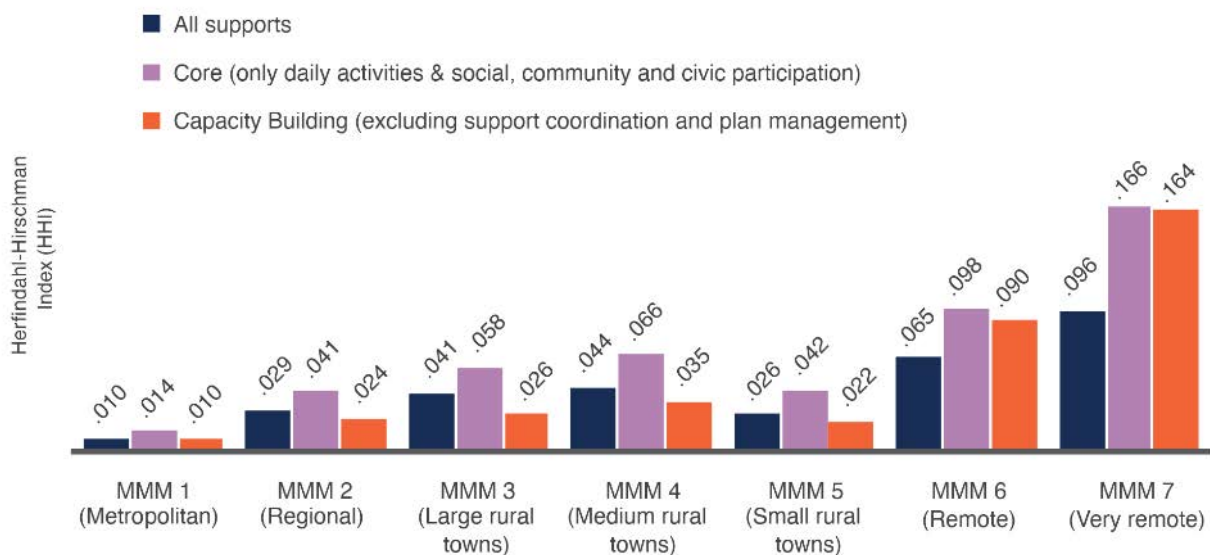
Note: The calculation in this figure will differ to a similar figure already published in the Review's paper on 'Improving access to supports for remote and First Nations communities' due to changes in data availability.

6.1.5 Alternative commissioning can lower demand risk and costs for communities

In failing to deliver safe, quality and timely supports and outcomes for participants in First Nations communities and for participants in remote communities, the current competitive market-based model also drives poor outcomes and upward pressures on the long term costs of the NDIS for these participants.

Failing to deliver participant outcomes in these communities puts pressure on the entire care and support ecosystem. A lack of timely supports may lead to increased hospitalisation rates or lengthier hospital stays, which in turn increases pressure on the primary healthcare system. Lack of local services can also drive demand for services in regional centres or capital cities away from country and demands for regular visits back to country.

Alternative commissioning approaches provide an opportunity to:

- Lower the cost of service delivery by offering service providers greater certainty of demand to invest in more effective service delivery models – this includes models that better coordinate and target investment in building and maintaining community infrastructure. Existing initiatives (including those by non-profit organisations, local, state or territory governments and the Australian Government) can be leveraged and built upon, while new initiatives could be better

targeted where need is most pressing. More effective service delivery models could also strengthen investment in local workforce, rely less on costly and ineffective FIFO and DIDO models and contribute to Closing the Gap.

- Improve health and wellbeing outcomes for both First Nations and remote communities using a more holistic, lifetime-based approach – for example, the *Far North Queensland Connect: Connecting people, connecting care* (FNQ Connect) noted "Improving integration of care and support will improve quality of life and health outcomes which will lead to a reduction in potentially preventable hospitalisations (PPH) and reduced pressure on the hospital sector over the medium-to-long term" (Case Study 29).[2050]

As outlined in the National Agreement on Closing the Gap, better life outcomes are also achieved when First Nations people have a genuine say in how their services are designed and delivered.

6.2. Implementing a placed-based, community-driven alternative commissioning approach

To be effective in improving service delivery for both First Nations communities and remote communities, alternative commissioning needs to follow a commissioning cycle. The cycle involves:

Understanding and building on communities' strengths and needs, including what initiatives and infrastructure already exist on the ground and can be built upon.
Exploring and designing solutions from the ground up, based on local needs and priorities.
Implementing the approach by selecting, overseeing, and engaging with providers and managing contracts. Implementation should also consider complementary policy or 'enablers', including: the role of intermediary supports, regulatory settings for ensuring appropriate quality and safeguarding, and pathways to access services.
Ongoing monitoring, evaluation and improvement.

Figure 152: Building blocks for alternative commissioning

Monitor, evaluate and improve
using a **practical and community-driven approach,** considering Indigenous data sovereignty, with best practice Indigenous evaluation and inclusion in the National Disability Data Asset (NDDA).

Understand community needs
through **strengths-based assessment and analysis of community's needs.**

Implement approach
through culturally appropriate, relational approaches to commissioning and contracting fit for purpose enablers, such as:
  – Access points and pathways into services
  – Regulation, workforce and infrastructure
  – Funding arrangements and assistance with coordinating and navigating supports

Explore and design solutions
including how community and NDIA decides if, and what, alternative commissioning approaches are needed.
Examples of alternative commissioning approaches
  – Direct commissioning
  – Community commissioning
  – Integrated commissioning

Effective governance is required for alternative commissioning to succeed. In First Nations communities this includes:
  – Share decision-making with First Nations communities.
  – Community-led design and implementation that builds on the communities strengths and addresses unmet needs
  – Sustainable and embedded place-based governance arrangements.
  – Accountability to national, overarching governance structures (*see Action 21.3*).

6.2.1 There are a range of alternative commissioning approaches

Alternative commissioning approaches are not returning to the 'block funding' arrangements that were used prior to the NDIS. Instead, they should provide participants, particularly those living in remote and very remote areas, with better continuity of services while offering choice and control over which service delivery model best suits the needs of the local community.

> *"Community control is the ultimate expression of voice and choice... they represent the most significant expression of voice and choice of Aboriginal communities who have taken control of their own health and human services" – Aboriginal Medical Services Alliance Northern Territory (AMSANT)[2051]*

Alternative commissioning approaches could be designed to coordinate demand for a number of NDIS supports within the community. Participants could flexibly access what they need, when they need. Design options could aim to set up service providers to deliver supports responsively to local needs and sustainably over the long term.

Alternative commissioning approaches could also be designed to coordinate demand for care and supports across disability supports (both within NDIS and foundational disability supports), as well as health, aged care and veterans' care supports.

Rather than separately funding different supports and community capacity building initiatives, funding for services could be more coordinated (or 'integrated') across programs to minimise duplication and gaps.

> *"Services in remote Indigenous communities are often poorly planned and uncoordinated, both between and within governments, and between service providers. Decisions about service provision are made on the basis of jurisdictional, departmental and program boundaries, and this may come at the expense of a focus on outcomes for users." – Productivity Commission[2052]*

Integrated commissioning approaches would make it clearer and easier for communities, particularly in remote areas, to understand what services they can access, from whom and when.

Having a single interface point for services, such as foundation disability supports, NDIS supports, aged care and veterans' care, can provide better wrap-around supports and services with smoother transitions across different life stages (see Chapter 1). For example, the FNQ Connect proposes developing a joint funding mechanism to align resources (Case Study 29).[2053]

For potential and existing service providers, integrated commissioning approaches may make it easier to achieve scale and reduce demand risk across the various care and supports needed in the community. Design of the enablers for alternative commissioning approaches may also make it easier for service providers to deliver supports in the community by reducing the complexity across different care and support program approaches.

Communities could also drive the design and lead the commissioning process for the supports they need. Community commissioning approaches could use different commissioning approaches, such as integrated commissioning. In particular, where there are already Aboriginal Community-Controlled Organisations (ACCOs) or Aboriginal Community Controlled Health Organisations (ACCHOs) in communities, First Nations communities should be able to have their say in designing the services they need and in commissioning the local ACCOs or ACCHOs to deliver these services.

Case Study 29: Far North Queensland (FNQ) Connect – a community-driven proposal for integrated care to address low and fragmented supply

FNQ Connect: connecting people, connecting care is a proposed model for disability, rehabilitation and lifestyle services for children, young people, adults and older people.

The FNQ Connect proposes to integrate and strengthen existing services in the 21 Local Government Areas which make up FNQ.[2054] The proposed model includes a network of community hubs that act as a 'one-stop-shop' for community rehabilitation services, information, education and advocacy. The proposed hubs' activities include:

- connecting care and support through shared health records, shared clinical governance and expansion of transition and navigation services

- strengthening the local community workforce and locally owned services through the development of certified workforce pathways and sustainable local services to match local needs

- building inclusive communities through inclusive policies, procedures, education and investment.

FNQ Connect is proposed to be an independent entity, guided by a *Leadership Table* led by people with lived experience of disability and representatives of Aboriginal and Torres Strait Islander communities, senior executives from key FNQ government, non-government and private stakeholder organisations. The *Leadership Table* would begin by developing a joint funding mechanism to leverage existing capacity and assets of agencies within FNQ Connect.

6.2.2 Approaches need to be underpinned by strong partnerships

Design and roll out of alternative commissioning approaches should be done in full and genuine partnership with communities, and should build on the strengths and capabilities already in communities.

Governments should ensure they meet their commitments under the *National Agreement on Closing the Gap* when working in partnership with communities. The most critical element of the alternative commissioning cycle is governance structures that share decision-making power with First Nations representatives and communities. This has been agreed to in the *National Agreement on Closing the Gap*, endorsed by all jurisdictions.

When place-based and led by communities, these approaches can contribute to Closing the Gap by strengthening the community-controlled sector and creating a more sustainable, localised workforce.

National Agreement on Closing the Gap

The National Agreement on Closing the Gap commits all Australian governments to work in full and genuine partnership with First Nations people to develop best practice policy to Close the Gap.

In exploring alternative commissioning approaches with communities, governments should ensure they continue to work in partnership with First Nations people and give effect to the four Priority Reforms in the Agreement (Figure 153).

The NDIA is taking some important steps towards building genuine partnerships with First Nations representatives and peoples.

At the national level, a formal partnership was agreed between the NDIA and FPDN, and the First Nations Advisory Council (FNAC) was established in February 2023. FNAC is co-chaired by the Chief Executive Officers (CEOs) of the NDIA and FPDN.

Being recently established, the extent to which the NDIA would genuinely share decision-making- with members of the FNAC remains to be seen. The Productivity Commission's draft report on the *Review of the National Agreement on Closing the Gap* found most government agencies have policy partnerships with First Nations people which currently function as consultative or discussion forums, "...with little if any authority for shared decision-making on significant policy matters".[2055]

Strong place-based partnerships would be necessary among communities, local First Nations organisations and experienced disability service providers. Working together, they should build each other's knowledge and understanding of disability, culturally appropriate ways of doing business and the individual community context.

Where available, governments would need to make the most of the expertise of local ACCOs and their connections to community.[2056] ACCOs would be essential business partners for governments and the community, and governments should enable ACCOs to lead the design and delivery of services that best suit their communities.

> *"The difference in upbringing, cultural knowledge and life in general does make a difference in communication and connecting that trust. I will always prefer Aboriginal worker for my children." – Carer of NDIS Participants[2057]*

However, it will take time for the NDIA to build these partnerships.

Figure 153: Governments must work in partnership to roll out alternative commissioning approaches that deliver against the four Priority Reforms in the Closing the Gap National Agreement

The Disability Sector Strengthening Plan

The Disability SSP also provides a framework of engaging with and responding to the needs of First Nations people with disability. All jurisdictions committed to the Guiding Principles (Figure 154) as a set of minimum standards when developing policies, programs, services and systems for First Nations people with disability.

Alternative commissioning approaches align with actions in the Disability SSP to implement localised community-led strategies to respond to thin NDIS markets. These Disability SSP actions include investing in the community-controlled sector to design and implement place-based approaches that address thin markets across Australia. The Disability SSP also outlines actions to facilitate a process for community-controlled organisations to provide NDIS services.

Figure 154: The 12 Guiding Principles in the Disability Sector Strengthening Plan

Principle 1: Human rights	**Principle 2:** Self-determination	**Principle 3:** Cultural integrity	**Principle 4:** Cultural safety
Principle 5: Partnership	**Principle 6:** Place-based	**Principle 7:** Innovation	**Principle 8:** Empowerment
Principle 9: Equity	**Principle 10:** Sustainability	**Principle 11:** Knowledge	**Principle 12:** Nationally consistent approaches

6.2.3   The timing of roll out should be community-led

Expanding new approaches in remote communities too far, too fast is a significant risk.[2058]

Roll out should be on a case-by-case basis, depending on each community's wishes, capacity and capability. For example, community commissioning approaches should draw on a community's capacity to lead the alternative commissioning approach.

First Nations communities in non-remote areas should have the option to choose whether alternative commissioning approaches could better deliver culturally appropriate NDIS supports to meet their needs.

Learnings and experience to date from the NDIS thin market trials also indicate that the NDIA needs to build its capacity and capability to roll out alternative commissioning approaches. Part of building NDIA's capability would be to ensure alternative commissioning approaches are rolled out using a strong basis (or 'building blocks') for alternative commissioning.

Commencing alternative commissioning pilots as soon as possible would help communities and governments to understand what works, and allow time to develop and strengthen partnerships with communities.

Following a discussion on our approach to alternative commissioning with Disability Reform Minsters in February 2023r[2059], the Australian Government announced a $7.6 million investment in partnering with communities to pilot alternative commissioning approaches for improving access to NDIS supports in remote and First Nations communities.[2060] The investment covers pilots in two communities, with the first pilot to commence with the remote community of Maningrida in the Northern Territory. DSS and NDIA should continue to be guided by First Nations communities in selecting further locations to pilot.

Funding of $27 million over four years was also announced in the 2023-24 Budget to trial integrated care and commissioning across primary health, First Nations health services, disability supports, aged care, and veterans' care in up to 10 locations across the country. [2061]

An evaluation of these pilots should inform how to progress the full roll out of alternative commissioning. The evaluation should also review the extent to which integrated commissioning approaches are preferred by both First Nations and remote communities and how they can improve outcomes for participants in these communities.

Over time, communities should be supported to buy and coordinate the supports for themselves. Communities could design the approach and lead the commissioning process.

To make sure these and future pilots have the best chance of success for communities and to support communities build the capability to undertake community commissioning, the Australian Government (including the NDIA and DSS) should draw on the findings of the Productivity Commission's draft report on the *Review of the National Agreement on Closing the Gap* and 2017 inquiry into reforming human services.[2062] This includes ensuring that:

- engagement with community is done in a culturally safe and respectful way which is at the community's pace and time
- adequate funding and timeframes are provided for communities to engage with governments so that an active understanding of, and genuine partnerships with, communities can be fostered
- designing service delivery approaches, alternative commissioning arrangements and service and program outcomes in genuine collaboration with communities so that they align with communities' needs, priorities, and measures of success
- more relational approaches to funding and contracting are adopted so that:

- funding is appropriate and covers the full cost of service delivery, including investments in infrastructure, capital works, building local workforce capacity and capability (see Section 7)

- there is adequate time for potential providers to build capacity and capability to respond to, and deliver services that meet communities' needs and priorities

- time is provided through setting up commissioning arrangements with contract terms for at least seven years. In remote communities, longer contract terms that incorporate contract reviews would allow extra time to establish community trust and invest in staff, capital and delivery models. In 2017, the Productivity Commission recommended ten-year default contract terms for human services in remote Indigenous communities.[2063]

> *"Over time, building the skills and capacity of people and organisations in the community could lead to more local service delivery. Any capacity building, or transfer of skills or responsibility should occur at a pace and in a way that suits the circumstances of the community." – Productivity Commission[2064]*

Effective feedback and governance mechanisms would be needed among DSS, NDIA and the local community.

- DSS should provide ongoing monitoring and coordinate the progressive roll out of alternative commissioning approaches in First Nations communities across Australia and for all participants in remote communities (see Actions 2.10 and 20.4).
- NDIA should build their operational capability to work in partnership with communities to explore, design and implement alternative commissioning approaches over time. This would include feeding back insights and learnings on an ongoing basis.
- Feedback from local communities should ensure voices of people in the community are central to decision-making and in understanding and measuring success (see Actions 20.4 and 23.5). The insights and learnings gained in local communities when building the community's capability to drive and lead the design and roll out of alternative commissioning approaches should be shared with other communities and also inform improvements to the overall alternative commissioning framework.

The evaluation of pilots must centre the voices of all people in the communities where alternative commissioning approaches are being explored (see Action 23.5). This should include adopting the approach to evaluation outlined in the *Indigenous Evaluation Strategy*.[2065]

Design of the approach to evaluation and key measures of success should commence as part of designing the alternative commissioning approach, and should be led and informed by the community.

Action 14.1: The <u>National Disability Insurance Agency</u>, in partnership with <u>First Nations</u> <u>representatives, communities, participants and relevant government agencies</u> to progressively roll-out alternative commissioning arrangements for both First Nations communities and remote communities, starting as soon as possible

The alternative commissioning approaches should be designed in partnership with First Nations representatives, communities and participants, and should be underpinned by governance structures that share decision-making power with communities (see Action 2.10), including First Nations representatives in non-remote communities as well as remote community representatives (which also encompasses the non-Indigenous local population). Alternative commissioning approaches should be based on a commissioning cycle that:

- Is underpinned by an understanding of, and builds on, community strengths and preferences
- Explores and designs commissioning approaches on a case-by-case basis with communities. This could include models of direct and community-led commissioning approaches as well as integrated commissioning (where a provider is commissioned to provide supports across multiple services types)
- Provides culturally appropriate, outcome-based commissioning processes, and
- Uses practical and community-driven processes to collect data and evaluate outcomes.

Implementation detail:

- A progressive roll out of alternative commissioning approaches should commence with pilots in selected communities. Pilots should be evaluated in partnership with communities.
- The evaluation should inform the wider roll out of alternative commissioning by drawing out lessons on how to build the capability of communities and governments to commission and the types of alternative commissioning approaches that work best. This should include considering the effectiveness of integrated commissioning in First Nations communities and for remote communities.

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7. A responsive workforce that delivers quality supports

- Over the past seven years, the NDIS workforce has more than doubled. Today some 325,000 workers across a diverse range of occupations and settings support NDIS participants, their families and carers.
- To fully meet demand, the NDIS workforce is forecast to need to grow by 40 per cent, or 128,000 workers, over the three years from June 2022 to June 2025. Demand is also growing across the wider sector – disability, aged care, and veterans' care. By 2049-50, demand for care

and support workers is projected to double – at which point almost 1 in 20 jobs in Australia are expected to be in the wider care and support sector.

- Developing a workforce of sufficient size and capability with appropriate attitudes to meet growing demand is critical to the effectiveness and sustainability of the NDIS and the broader care and support sector. However, care and support jobs can be short term, with variable hours, high turnover, poor conditions and poor career prospects. A relatively high share of workers work multiple jobs and employers have few incentives to upskill their workers.

- Efforts to improve worker attraction and retention are needed to support career pathways, improve the quality of supports, and lower turnover and the associated costs to service delivery.

  - New approaches to training and leave could reward workers for staying in the sector and building their skills, without being required to stay in the same job. Schemes that allow for portability of training and sick and carer's leave entitlements could be a way to do this. But these schemes need to be tested to ensure they deliver overall benefits and are not unduly burdensome. This would complement the progression of micro-credentials (short courses or competencies), a digital skills passport and growing the use of traineeships.

  - Peer workers are a critical, but underutilised, part of the sector. Increasing the representation of people with disability in the NDIS workforce will not only improve outcomes for people with disability but also improve the quality of support provided. This should start with increased support for individual and family capacity building being delivered by peer workers as part of the increased investment in foundational supports. As demonstrated by Assistive Technology Australia, there are untapped opportunities for assistive technology peer mentors and workers.

  - Policy approaches to strengthening pathways into the sector are also needed. Industry labour agreements are one tool that can respond to acute labour shortages and be targeted to workers with suitable skills, values and attitudes.

- Reforms to how the NDIS operates are equally important to supporting a responsive and capable workforce. Quality and safeguarding reforms for workers are needed to better balance improved safety outcomes for participants with steps to make it faster and simpler to join the sector. Reforms are also needed to better support NDIS providers to build and retain a quality workforce.

- Early intervention supports and improved uptake in assistive technology and home modification supports would assist participants to be more connected to their community and potentially reduce workforce pressures.

Recommendation 15: Attract, retain and train a workforce that is responsive to participant needs and delivers quality supports

- **Action 15.1: The <u>Australian Government</u> should design and trial workforce attraction and retention initiatives.**

- **Action 15.2: The <u>Australian Government</u> should develop targeted and flexible migration pathways for care and support workers.**

- **Action 15.3: The <u>Australian Government</u> should develop an integrated approach to workforce development for the care and support sector.**

7.1. The needs of the future NDIS workforce

The essential care and support provided by NDIS workers throughout the COVID-19 pandemic has been critical. The strain of the past few years has no doubt been felt by many NDIS workers. This strain, however, goes beyond the impacts of the pandemic to the key challenges facing the NDIS workforce.

The NDIS workforce, working across registered and unregistered providers, has grown and evolved through the scheme's transition phase. On a full-time equivalent basis, the NDIS workforce has grown from around 74,000 in June 2015 to 202,000 in 2021-22.[2066] The actual number of workers supporting participants is much higher still at around 325,000 in 2021-22.

Figure 155: The NDIS workforce is diverse, covering disability support workers, allied health workers and other workers working across a variety of settings[2067]

Disability support workers

280,000 workers in 2021-22

385,000 workers needed by June 2025

8 in 10 work part-time

7 in 10 are female

6 in 10 aged 44 or under

Allied health workers

36,000 workers in 2021-22

51,000 workers required to fully meet demand by June 2025

This group includes both allied health professionals and allied health assistants. In the year to 20 September 2022, allied health services accounted for around **13% of NDIS payments.**

Across the broader care and support workforce

4 in 5 hold a Certificate III qualification or higher, compared with 66% of the broader labour market. Enrolments in relevant VET qualifications increased by around 6.5% between 2015 and 2019, however, completions declined by 4.6%.

Almost **4 in 10 were born overseas**, compared to 32% of the overall workforce.

Other workers

9,000 workers in 2021-22

17,000 workers required to fully meet demand by June 2025

These workers provide a **diverse range of supports** and include, for example, support coordinators, interpreters, gardeners and cleaners.

Emerging platform workers

The number of workers supporting NDIS participants through online platforms **is small, but growing.**

In 2021-22, around 16,000 NDIS agency and plan managed participants had used a platform provider.

Informal carers

In 2018, there were an estimated **2.65 million informal carers of people with disability and older people.**
Around 1 in 3 (861,000) were primary carers.*

In 2020, it was estimated that informal carers delivered nearly **2.2 billion hours of care** which would cost **$77.9 billion** if delivered by formal carers (i.e. paid workers).

Primary carer refers to someone who supports a person of any age with a disability. Informal carers includes those who support people of all ages with disability and older people (aged 65 years and over) without disability.

Participants, families and carers told us of the difference good support workers can make in their lives.

> *"I have been linked with the most amazing support workers. People who work for me in their own time to fill the many, many gaps left by an inadequate plan. [If] it were not for the wonderful humans who support me so well, I guarantee you I would have checked out." – Participant*[2068]

As the NDIS grows, more workers will be needed to support people with disability. About 128,000 more workers are likely to be needed by June 2025 to fully meet NDIS demand.[2069] But participants, families and carers told tell us that finding and keeping disability workers with the right skills, values and attitudes is already hard today.

> *"Finding good support workers has been very difficult for us. I have often gone unsupported due to [being] unable to find good workers for our daughter." – Carer*[2070]

Additionally, unless the high level of turnover can be addressed, the number of new workers who need to enter the NDIS will be higher still. In a given year, indicatively between 17 per cent and 25 per cent of NDIS workers leave their job. In comparison, 12 per cent of workers across the economy left their job in 2021.[2071]

Assuming 17 per cent to 25 per cent average annual staff turnover, between 198,000 to 292,000 workers are expected to be lost due to churn in the three years to June 2025.[2072]

Developing a future workforce of sufficient size and capability to meet growing demand for safe and quality supports is essential to securing the future sustainability of the NDIS.

The NDIS workforce, however, does not operate independently from the wider care and support sector. Meeting future NDIS workforce demand is unlikely to be achieved without significant action by governments to address shortages and improve the productivity of the overall 'care and support' workforce.

Care and support sector workers – including disability, aged care and veterans' care and support workers – are known to transition between, or even work concurrently in, different parts of the sector.[2073]

Many roles across the sector share similar skills requirements and attributes. That said, not all roles and jobs are transferrable, with some specialised services and roles required for different participants and clients. Importantly, disability support workers need to be aligned with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and support participants to build capacity and achieve their goals.

While data on the numbers of workers working across disability, veterans' care and aged care is not available, providers often operate across programs implying many workers also do so. Around 35 per cent of aged care providers and 85 per cent of veterans' care providers deliver services across two or more registered care and support programs. Although only 6 per cent of registered NDIS

providers also provide aged care and/or veterans' care supports – the lower share reflects the relatively large number of registered providers.[2074]

Large workforce gaps must be considered at a whole-of-sector level. Any attempts to reduce the NDIS workforce gap without considering the broader care and support workforce (including, how prices are aligned across the sector for government funded supports) could exacerbate shortages of workers elsewhere.

An integrated approach to building the care and support workforce is required.

By 2049-50, demand for the care and support workforce is projected to double – at which point almost 1 in 20 jobs are expected to be in the care and support workforce.[2075] However, a significant shortfall of workers is projected across the sector – concentrated in the occupation groups Aged and Disabled Carers and Nursing Support and Personal Care Workers.

Figure 156: Service providers operate across the care and support sectors[2076]
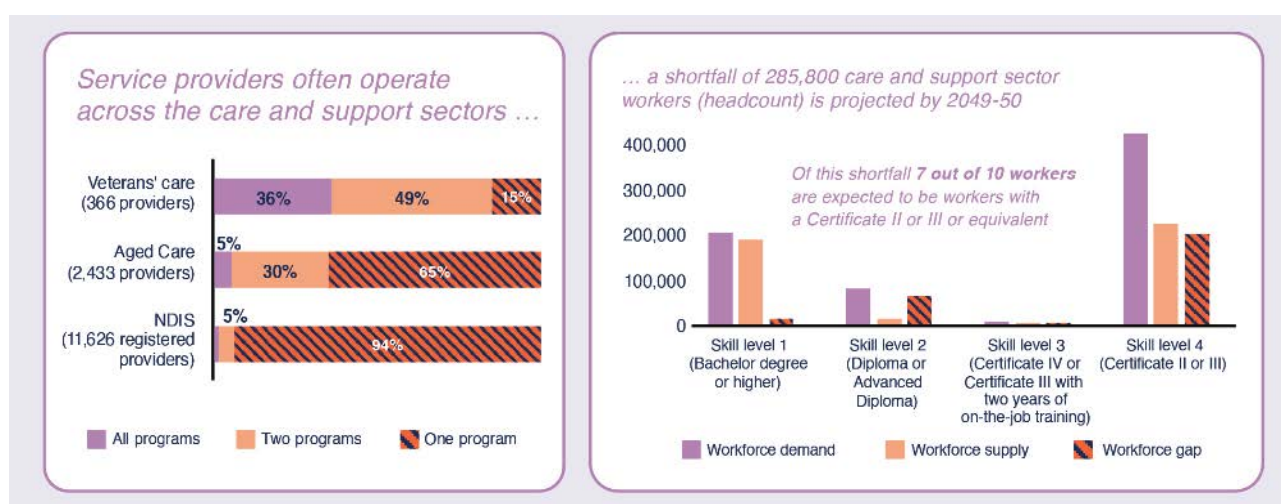
Note: The chart on the left is based on DSS analysis of NDIS, aged care and veterans' care registered providers as at 30 June 2020. The chart on the right is based on analysis performed by Deloitte Access Economics in 2021, which was commissioned for the Care Workforce Labour Market Study.

Numerous past reviews and strategies have considered the barriers to attracting and retaining an appropriate supply of care and support workers. Yet there remains a largely fragmented approach to addressing workforce issues across the sector. For instance, while in May 2023, a new labour agreement to streamline the recruitment of direct care workers commenced, this agreement was limited to aged care providers (see Box 87).

Workforce reviews and strategies have too often taken a siloed approach to developing program-specific solutions. While some reviews and strategies have highlighted the need to better coordinate workforce development initiatives across the care and support sector, they have not consulted widely with affected workers across the entire sector. [2077]

Past workforce strategies have also lacked accountability on how outcomes would be measured, making it difficult to tell if government actions have had any impact to date.

"While monitoring and evaluation of the [NDIS Workforce] plan is expected throughout its life, the plan itself does not set out measurable outcomes that might be used to assess whether the plan is effective in supporting sustainable growth in the NDIS workforce. … The committee therefore remains concerned that, without adequate attention from the Commonwealth Government in this plan, many of the issues experienced by the NDIS workforce … will continue to persist." – Joint Standing Committee on the NDIS [2078]

Figure 157: Numerous reviews and strategies have examined issues in the care and support workforce

7.2.   Workforce challenges are well known and widespread

The NDIS workforce has been experiencing acute pressures over the past few years, exacerbated by the onset of the COVID-19 pandemic, the closure of international borders and pronounced worker shortages. Around half of NDIS workers have reported that the pandemic made their work experience worse.[2079]

But even before this, persistent workforce challenges in the NDIS were widely known.

Workforce challenges are driven by multiple factors. Care and support jobs can be short term with high turnover, poor conditions, limited career prospects and poor incentives for disability support workers to become supervisors. Around 2 out of 5 NDIS workers (43 per cent) feel burned out at least half the time in their job.[2080]

Workers are leaving NDIS jobs at a faster rate compared to the wider economy. A relatively high share of workers work multiple jobs. This means employers face little incentive to invest in training workers.

Retention challenges were reported to be related to burnout and COVID-19 fatigue, as well as a lack of career pathways, the casualised nature of the work, low pay rates and leaving for 'easier' work in different sectors.[2081] A tight labour market creating increased competition for workers also plays into retention issues.

> *"There is a vicious cycle in this sector. People want to make a career as a disability worker. They know that they need to be trained to do the sort of specialised work that is needed. They want to do that training. But they cannot do it [training] because they are employed only on a casual basis with short contracts and so must work for several organisations just to make ends meet. This means that they cannot refuse a shift because they cannot risk losing that job. If they cannot get time off, they cannot do training. If they do not do training, they cannot get more shifts – because they do not have the specialised training needed for the work. How do they win?" – Disability Support Worker, quoted in Australian Services Union[2082]*

7.2.1 There are opportunities to modernise the training system

Few workers in the sector work in traditional full-time ongoing employment, where the relationship between the worker and the employer is usually over a longer period and both workers and employers share in the benefit of upskilling. Training systems, regulation and market settings, however, are not well set-up to support ongoing learning and career development for workers in non-traditional jobs.

Workers report having limited access to training and supervision.

> *"Supervision is few and far between, that's if it does happen. We aren't debriefed after extreme major incidents. We're constantly questioned about doing overtime when we're understaffed. We haven't had a staff meeting since 2022." – Disability Support Worker, quoted in Health Services Union[2083]*

Issues with access to training and supervision may be exacerbated for the few workers who opt to move across to work independently, including via emerging platforms. However, some workers value the flexibility, autonomy and potential for higher pay when working as an independent contractor, helping keep them in the sector.[2084] The Productivity Commission found alternative structures for aged care employment, including platform workers, are an important part of meeting workforce demand.

Attracting and retaining capable workers in the NDIS will require a shift in the current training models and infrastructure. The future training system will need to adapt to provide effective models of on -the job and progressive learning.

7.2.2 There are opportunities to improve career pathways across the sector

Removing barriers to workers transitioning over time between jobs in different parts of the care and support sector would open up opportunities for workers to build their career, both within, and across disability, aged care and veterans' care.

These opportunities would help to keep workers in the sector. They would also support the dissemination of knowledge, practices and the use of labour-saving technology (such as more efficient rostering systems).

7.2.3 Building the size of the workforce will be key

As the scheme matures, greater investment in early intervention supports as well as capacity building, assistive technology and home modification supports could help improve outcomes for participants and reduce growing pressure on the workforce. For every dollar of funds allocated to participant capacity building and capital supports budget, only around $0.60 is currently spent.[2085]

That said, improving the effectiveness of the NDIS by itself will not solve the care and support workforce shortage. Solutions will need to consider how to bring more workers into the care and support sector.

Drawing on current workers in the sector will help. Just over 1 in 10 care and support workers (13 per cent) were underemployed in February 2021.[2086] That is, around 1 in 10 workers worked less than 35 hours per week, but were willing and able to work additional hours. In comparison, across the economy 9 per cent of workers were underemployed. [2087] (Recent tight labour market conditions has seen underemployment rates across the economy fall to around 6 per cent in late 2022).[2088]

Yet, this is not a panacea for future workforce needs. For personal care and support workers, just over half of underemployed workers in the sector were willing and available to work up to 9 additional hours per week.[2089]

Attracting workers in sufficient numbers must involve improving the desirability of care and support work to draw in workers from sectors where technological change is reducing opportunities for labour and to bring in those outside the labour force.

Figure 158: Key workforce challenges[2090]

Key workforce challenges

Workers holding multiple jobs

Around **11% of the care and support workforce reported holding multiple jobs**, compared with around 6% of the overall workforce. Almost **two-thirds holding multiple jobs were personal care and support workers**. (National Skills Commission 2021).

Participant preferences at the beginning and end of the day, coupled with broken shift allowances in the Social, Community, Home Care and Disability Services Industry Award (SCHADS Award) can mean "... it is more cost effective for providers to employ multiple disability support workers to provide services to one participant in order to avoid paying additional allowances." (National Skills Commission 2021).

High workforce turnover

Indicatively, NDIS workforce turnover is between 17–25%. Whereas, in 2021, turnover was 7% in the broader health care and social assistance industry and 12% for all industries (Department of Social Services 2021).

A recent NDIS workforce retention survey by the Behavioural Economics Team of the Australian Government (BETA) found around **1 in 4 part-time and casual contract NDIS workers were planning to leave their job in the next year**, compared with less than 1 in 5 (18%) of full-time workers (BETA 2023).

Retention challenges appear have become more acute since 2020. More than half (56%) of 364 surveyed providers reported difficulty retaining disability support workers in 2022, up from 40% in 2020 (National Disability Services 2022).

Workers holding multiple jobs

A workforce retention survey of 768 NDIS workers conducted by BETA found **43% felt burned out at least half the time in their job, including 12% who almost always felt burned out**.

High workloads, health and safety risks, personally confronting work and dealing with administration and red tape were associated with increased burnout. (BETA 2023).

More frequent feelings of WHS risk was linked to workers' plans to leave the NDIS workforce. In 2020-21, aged and disability care workforce reported 11.1 workers compensation claims per million hours worked, compared with an average of 6.5 claims per million hours worked for all occupations. (Safe Work Australia 2022).

High levels of part-time and casual work

Around **three in four NDIS workers are employed part-time** (that is, they worked less than 35 hours per week). Part-time work in the sector can often have minimal guaranteed hours (Productivity Commission 2022).

A high share of NDIS workers are not employed on a permanent basis. The **rate of casual employment (37%)** is high relative to the broader health care and social assistance industry (18%) (National Disability Services 2022).

Limited access to training and supervision

In 2020, **1 in 4 (26%) NDIS workers reported receiving less than 1 day of training in the past year**. A third (32%) received between 1 and 2 days of training, and 43% received 3 or more days (Cortis and van Toorn 2020).

Just over **1 in 3 workers (36%) agreed they received the supervision needed**. This was **lower for casual workers, with 1 in 4 (26%) agreeing they received the supervision needed**. The same survey found that **more than half of workers with supervisory responsibilities (53%) agreed they could not provide proper supervision due to a lack of time** (Cortis and van Toorn 2020).

Different regulatory arrangements can provide a barrier to working across the care and support sector

Differences in regulatory arrangements include **worker screening requirements, training and qualification requirements**. For example, a worker with an NDIS worker screening check can have this recognised in the aged care system, however an aged care worker with a police check will still need to obtain an NDIS worker screening check to work in the NDIS.

Workforce availability in regional and remote locations

The Joint Standing Committee pointed to workforce challenges in regional and remote locations driven by: **higher costs of service delivery, higher staff turnover, travel costs, low numbers of service providers and professional isolation**.

The NDS noted workforce challenges were compounded in some areas by inadequate or overcrowded housing; poor community infrastructure; inadequate and expensive transport; and shortages of income to meet basic needs. (Joint Standing Committee on the NDIS 2022).

7.2.4 Realising these opportunities will require targeted policy action

As major funders of care and support services, governments would benefit from putting in place the infrastructure and policies to support workforce development and ensure the effective, efficient and sustainable delivery of supports.

Targeted action is needed across a number of policies.

- **Pathways and advancement into the care and support sector**. Governments need to address barriers for workers to move across the care and support sector. Putting in place systems to support mobility could support career progression and encourage workers to remain within the broader sector.
- **Scheme rules and procedures are critical to supporting a responsive and capable workforce**. Moving the dial on meeting workforce challenges will also require reforms to how the NDIS is set-up and operating. Regulation and market policies aim to ensure the delivery of safe and quality NDIS supports that are responsive to participants. However, these policies also shape how providers deliver supports and workforce outcomes.

> **Box 82: New approaches are needed to attract and retain capable staff to the care and support sector to address workforce challenges**
>
> To attract workers in sufficient numbers to meet future demand, the desirability of care and support work needs to be improved. The sector needs to draw in workers from sectors where technological change is reducing opportunities for labour and to bring in those currently outside the labour force.
>
> Removing barriers to workers moving between jobs in different parts of the sector would open up opportunities for workers to stay in the sector – to build their career across disability, aged care and veterans' care. Moving away from 'linear' ways of providing training to be able to improve their skills progressively would also benefit workers who often work below full-time hours or in casual and non-ongoing arrangements.

7.3. Supporting workers to remain and advance in the care and support sector

Evidence from Australia and England suggests that turnover for care and support workers is highest within the first year of employment. In England, care workers with less than one year experience had a turnover rate of around 44 per cent compared with 24 per cent for workers with five years' experience. In Australia, the National Skills Commission noted turnover in the occupation Aged and Disabled Carers in the first year of employment was a significant challenge for providers.

Supporting workers to remain and advance in the care and support sector will need to consider new approaches to training and new ways to support workers, considering the flexible nature of many care and support sector jobs.

7.3.1   New approaches to training are needed

Ongoing skills development and training is crucial to ensuring that workers develop their knowledge and skills and can provide safe and quality supports to NDIS participants. Ongoing training is also essential for workers' to further develop their skills and progress their careers.

The current training structures in the NDIS, however, are not working. Employers have few incentives to invest in training workers.

In its Interim Workforce Report, the Joint Standing Committee on the NDIS heard there is insufficient training provided in the sector – particularly to disability support workers.

> *"The disability workforce is often required to self-fund training, as employers are unwilling or unable to deliver training under current price settings. In the absence of proper training, workers will have difficulty providing safe, quality services to participants, and may experience increased health and safety risks." – Joint Standing Committee on the NDIS[2091]*

Initiatives to modernise the training system are needed to support progressive learning and upskilling – particularly for support workers.

Growing the number of traineeships for entry-level workers, micro-credentials and a digital skills passport are important modernising initiatives already agreed and underway. Greater use of traineeships, for example, could provide alternative pathways, for workers to complete the Certificate III in Individual Support, bypassing the need for 120 hours of mandatory unpaid work placement.

Box 83: Traineeships combine training with a Registered Training Organisation (RTO), practical work experience and on-the-job training

- Enable learners to 'earn and learn' and lead to attainment of an accredited qualification, such as a Certificate III in Individual Support or Certificate IV in Disability.
- 'Aged or Disabled Carers' and relevant Certificate III and IV qualifications are currently listed on the Australian Apprenticeships Priority List.[2092] This means that both employers and trainees are eligible for a range of Australian Government incentives and subsidies through the Australian Apprenticeships Incentive System Program.
- Employers of apprentices and trainees in priority occupations can claim a wage subsidy over the first three years of the apprenticeship or traineeship, up to $15,000 in total. Eligible workers in priority occupations can also receive up to $5,000 in direct support to assist with the cost of living while they are completing their apprenticeship (part time workers receive up to 50 per cent, or $2,500). These incentives are available to eligible apprentices and employers who commence training prior to 1 July 2024.

Micro-credentials support career pathways in the care and support sector

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- Microcredentials are short courses or competencies that can be used to rapidly upskill and reskill the workforce. Micro-credentials can also be combined with other competencies to build knowledge and skills into full qualifications.[2093]

Digital skills passport

- A digital skills passport, once developed, would provide a practical tool to help workers record and track their training – including micro-credentials and unaccredited training – supporting workers to build towards a full qualification and removing barriers to working across the care and support sector.[2094]

The *NDIS National Workforce Plan: 2021–2025* identified all three as priority actions. We consider that these initiatives should apply across the care and support sector and should be progressed as a priority. Over time, as part of the digital skills passport, workers could potentially showcase their skills and qualifications through the worker screening database (see Recommendation 17).

Other existing initiatives could also be built on to support training.

Growing student placements, particularly for allied health students, in disability and aged care settings could help build connections and career pathways to the sector, as well as improving the capability of allied health professionals.

The existing NDIS Workforce Capability Framework describes the attitudes, skills and knowledge expected of all workers in the NDIS. The Framework has been leveraged in the development of training materials for NDIS workers including the Certificate III in Individual Support and Certificate IV in Disability Support, which were revised at the end of 2022.[2095] It will be important to review the impact of these changes to ensure they are improving workers' understanding and ability to deliver supports within a human rights framework. If successful, the NDIS Workforce Capability Framework should be used in the development of training materials across the care and support sector. Even so, more needs to be done.

A key barrier to undertaking ongoing training is the time required to undertake training, particularly if unpaid. A portable training scheme, which could fund paid time off as well as course costs, could assist in addressing this barrier.

This is not a new proposal.

> *"… a number of countries acknowledged the need to put in place systems of lifelong learning that could deal with increasingly non-linear career paths and support individuals as they move between jobs, careers, training and other absences from the labour market throughout their lives. One important element of this is portability of training rights and the portability of skills themselves." – OECD[2096]*

An example is in France, which introduced the Compte Personnell de Formation (CPF), a personal training account scheme in 2015. The CPF is a scheme for financing training that is linked to individuals and fully transferable throughout a person's working life. The CPF is funded through an employer levy. Self-employed workers pay a flat-rate contribution.[2097]

In 2018, the Joint Standing Committee on the NDIS recommended that the NDIS Commission review options on how to ensure disability workers under the NDIS can access funded training, including considering the introduction of a portable training entitlement system.[2098]

The Centre for Future Work's 2018 report on *A Portable Training Entitlement System* for the Disability Support Services Sector, proposed a system where disability support workers would be credited 1-hour of paid training for every 50 hours of NDIS-funded work. Under the Centre's proposed scheme, credits would be vested with individual workers, allowing them to accumulate credits even if they work for multiple employers or as sole traders.[2099]

The Australian Services Union (ASU), which commissioned the Centre for Future Work's report, stated in a submission that "… funding support for the worker to take the time to complete the study [was] a critical component to support course completion in a low-wage, insecurely employed, fragmented workforce".[2100]

We consider there are potential benefits to a portable training scheme for the care and support sector.

That said, as with any scheme, it will be important to ensure design and implementation of the scheme achieves the intended policy outcome and avoids unintended effects.

Key design features include:

- **system infrastructure** – for the scheme to enable applicability across the broader care and support sector. This would need to include a mechanism to link training credits to hours of work performed across multiple providers
- **eligibility criteria** – including the threshold to establishing an account for workers, and whether accredited or non-accredited courses (or both) would be eligible
- **funding approach** – that is, if the scheme should be funded via industry, government, through participant funding packages or a combination.

We consider there are benefits in trialling a portable training scheme across the care and support sector. The design of a proposed scheme and the trial should be developed in close consultation with care and support workers, employers and participants.

It is worth highlighting that as the major funders of care and support services, governments would implicitly fund such schemes one way or the other. As such, the trial should be designed to evaluate the contribution portable training makes to supporting the size and capability of the care and support workforce, and consider if training would be better supported using alternative arrangements so as to be most effective in terms of securing the care workforce of the future.

7.3.2 Supporting workers to remain in the sector through portable leave arrangements

The flexible nature of many care and support sector jobs is part of a broader shift to various forms of non-standard employment. How to best support workers engaged in these types of work, including how to support lifelong learning, is a question that has been examined in both Australia and internationally.

> *"Those in new forms of work may face multiple barriers to lifelong learning. While employers can play a significant role in providing training opportunities, they may see a greater return on investment for training on employees on full-time, open-ended contracts compared to workers on fixed-term, part-time or casual contracts. The same workers, as well as self-employed own-account workers, may have reduced access to publicly funded training programmes, often designed with standard employees or the unemployed in mind. ... A number of countries reported that they were taking action to encourage participation in lifelong learning among workers in new forms of work."*
> *– OECD[2101]*

The COVID-19 pandemic accelerated public debate on the merits of expanding paid leave entitlements to more types of workers, including casuals and contractors. In June 2021, the Senate Select Committee on Job Security recommended the Australian Government undertake a review of the current portable leave schemes and examine where such schemes could be extended to workers in other industries, in consultation with employer and employee groups, and state and territory governments.[2102]

Industry-specific portable long service leave schemes are operating in some states and territories. This includes schemes that already cover disability workers in Queensland, Victoria and the ACT (see Box 84). The NSW Government also recently announced a consultation process on extending portable long service leave to community service workers, citing a recent survey by the NSW Council of Social Service which found the care sector in NSW could lose up to 120,000 workers over the next 5 years, with poor pay and insecure work driving staff out.[2103]

While portable long service leave could support retention of workers in the sector, there is a lack of robust evidence on the effectiveness of these schemes. In addition, by its nature, long service leave has a long qualifying period and, therefore, does not address the high volume of turnover during the first year of employment in care and support jobs.

Portable arrangements for sick and carer's leave do not exist on the same scale as portable long service leave arrangements. However, these schemes may help with early retention issues, as workers are supported and rewarded early for continuing to work in the sector, without requiring them to stay in the same job.

Incolink, an industry-led worker entitlement scheme covering construction workers in Victoria and Tasmania, provides portable sick and carer's leave to employees of participating businesses. Under the scheme, when a construction worker has exhausted their sick and carer's leave entitlement from their current employer, they become eligible to use leave from a previous employer (capped

at 100 days).[2104] The scheme is only available to workers who have an entitlement to sick and carer's leave, that is, it does not cover casual or contract workers.

In 2015, Nous Group undertook an evaluation of Incolink's various benefit programs (including portable sick and carer's leave) which estimated the annual net benefit to be $4 million per annum attributed to the portable sick and carer's leave scheme.[2105]

Box 84: Industry-specific portable long service leave schemes operate across Australia, with some already applying to care and support workers

The Queensland, Victorian and ACT governments operate portable long service leave schemes covering the community services sector within their jurisdiction – covering disability workers and some other care and support sector workers. Principles underpinning these schemes are broadly similar (see table below).

Eligibility for leave is based on time served in an industry, rather than with a single employer. Schemes are funded through an employer levy on wages and paid into a central fund. When a worker becomes entitled to long service leave, their entitlement is paid out of the central fund and not by their current employer.

	Queensland	*Victoria*	*ACT*
Commenced	1 January 2021	1 July 2019	1 July 2010
Leave Entitlement	6.1 weeks	6.1 weeks	4.33 weeks
Worker Service Required	7-years	7-years	5-years
Employer Levy	1.35 per cent of ordinary wages	1.65 per cent of ordinary wages	1.6 per cent of ordinary wages
Blanket Exclusions	Commonwealth, State and Local Government workers	Commonwealth, State and Local Government workers	Commonwealth and Territory workers

Which care and support sectors are covered?

	Queensland	*Victoria*	*ACT*
Disability	Yes	Yes (1 January 2020)	Yes
Aged care (in-home & community)	Yes	Yes	Yes (1 July 2016)
Aged care (residential)	No	No	Yes (1 July 2016)

Note: while these three schemes can apply to independent contractors/sole traders, payment of the levy is optional.

When establishing its new portable long service leave scheme for the community services sector, the Queensland Government's Office of Industrial Relations suggested the scheme would provide "… considerable benefits for the sector in the attraction and retention of skilled and experienced employees which will be realised in reduced recruitment and training costs over time and a stronger more resilient workforce to support Queensland communities".[2106]

The Victorian Government recently commenced a pilot – *Victorian Sick Pay Guarantee* – to provide eligible casual and contract workers up to 38 hours per year of sick and carer's leave paid at the national minimum wage. The pilot commenced in March 2022 and will run until March 2025.[2107] Aged and disability care workers are one of the occupation categories included in the Victorian pilot.[2108] As at 5 January 2023, around 55,000 workers had registered for the program and 80,000 payment claims had been processed.[2109] The Victorian Sick Pay Guarantee pilot is funded directly by the Victorian Government.

We consider that a national sector-wide portable sick and carer's leave scheme could support the retention of workers across the care and support sector. This could help workers stay in the sector and support early career progression opportunities. Participants, governments and providers may benefit from increased dissemination of knowledge, practices and the use of labour-saving technology.

Making it easier for workers to move across the care and support sector can open up more career options and encourage them to stay in the sector. Lowering turnover would not only improve the continuity of supports to participants but also lower the cost of delivering supports. The Australian Services Union highlighted two case studies where service providers estimated the direct costs of on-boarding a new disability support worker was between $2,130 and $3,320, with one provider noting that "it generally takes a full month of working before they reach acceptable competence".[2110]

However, scaling-up to implement a portable sick and carer's leave scheme is not without drawbacks. If not well designed, a portable sick and carer's leave scheme could unintentionally push more workers to casual work (where employees are entitled to a 25 per cent casual loading in lieu of access to paid leave entitlements). Efficient administrative arrangements will also be key to ensure any scheme delivers benefits to the sector overall. In the case of an employer levy funded scheme, providers would also need to make provisions for sick and carer's leave liabilities.

Further consideration is needed on the costs and benefits of any national sector wide portable sick and carer's leave scheme.

We consider a scheme should be first designed, trialled and evaluated before any further roll -out. Central to any scheme design would be eligibility considerations, how it would interact with existing legislative and regulatory requirements, who would be responsible for funding the entitlements and any implications for NDIS prices and pricing and payments approaches.

Complementary initiatives to develop micro credentials, a digital skills passport and support to grow the use of traineeships for entry-level workers, which have already been agreed for the NDIS, should be progressed as a priority across the care and support sector.

Further opportunities could also be explored for greater use of technology that **can support the upskilling of workers**. In communities where alternative commissioning approaches are used (see Recommendation 14), design and funding of the alternative commissioning arrangements could

consider investing in technology (such as tele-disability and telehealth), as well as the infrastructure and capital needed to build the workforce capacity and capability across the whole community.

7.3.3   Action & Implementation Details

Action 15.1: The <u>Australian Government</u> should design and trial workforce attraction and retention initiatives

The Australian Government should work with states and territory governments to design and trial initiatives to attract, retain and train the care and support sector to better understand what will work to provide the care economy workforce for the future.

These initiatives should include designing and trialling a portable training scheme and a portable sick and carer's leave scheme, in close consultation with unions, disability and other care and support workers, employers and participants/clients. The trial of the portable training scheme should commence urgently and could initially focus on disability support workers.

Both trials should give consideration to the system infrastructure, eligibility criteria and funding approach that would ensure benefits exceed costs and the scheme would be widely adopted.

Complementary initiatives to develop micro credentials, a digital skills passport (potentially through the worker screening database, see Action 17.4) and support to grow the use of traineeships for entry-level workers, which have already been agreed for the NDIS, should be progressed as a priority across the care and support sector.

Opportunities to align the NDIS workforce needs with other government initiatives, such as reforms to the Community Development Program in remote First Nations communities, should be used to benefit people with disability and these communities.

7.4.   Strengthening pathways into the sector

To meet future workforce needs, the care and support sector needs to do much more to attract workers.

7.4.1   Attracting workers with the right attitudes, values and personal attributes is critical

A 2017 survey of care and support employers found that employee attributes are particularly important for disability providers, with employers ranking personal qualities as more important than both qualifications and experience.[2111] These include cultural sensitivity and awareness, dependability, attention to detail, willingness to learn new things and communication.[2112]

Participants place high value on workers' having a knowledge of disability and the human-rights framework underpinning the NDIS.[2113]

To this end, the NDIS Commission's existing Workforce Capability Framework provides a -self-assessment tool for prospective workers to check if they would be suitable for, and interested in, work in the NDIS.

The Department of Employment and Workplace Relations has also developed an online self-reflection tool to assist jobseekers to reflect on their values and working style and help them consider whether they will be a good fit for work in the broader care and support sector. The tool also makes suggestions on which areas of the sector might be a better match for them. To help improve awareness of the job opportunities in the sector, the Department also developed a short video that provides an introduction to the range of roles in the sector.

If effective, these tools should assist with better matching workers, lowering the cost to businesses and participants associated with high turnover in the sector.

State and territory governments have also implemented a number of employment programs which seek to provide tailored solutions when matching jobseekers to local jobs (see Box 85). These programs aim to provide tailored solutions for workers as they transition into the sector.

However, without program evaluations, it is not possible to understand the extent to which these approaches were able to up-lift workers into the sector. This highlights the need to embed evaluation early in program design.

Box 85: More evidence is needed on understanding what works to attract workers into the sector

'More Jobs More Care' initiative in NSW provided new workers with holistic supports

The NSW Government Initiative provided funding for 2,500 individuals to undertake a free four -week pre-employment program which provided a pathway into a job as a disability support worker. The program targeted school-leavers as well as people who lost work due to the pandemic. Key elements included:

- delivery of at least four accredited learning modules, including a First Aid Certificate. These modules count towards a Certificate III in Individual Support if learners opted to continue training
- 15-hours of workplace-based training
- mentoring and support for learners during training as well as ongoing professional development support upon commencing work
- payment for relevant worker screening checks.

'Jobs that Matter' initiative in Victoria

The Victorian Government ran a public campaign to boost workforce attraction in the community service sector. The Jobs that Matter campaign provides information about employment in this sector, the contribution it makes to the lives of Victorians, and the

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opportunities available to support the community services workforce in 2021-22 and beyond.

The program included three phases:

- awareness, which showcased the sector and opportunities available
- an integrated recruitment campaign to build the community services workforce

targeting youth by putting the community services sector on the radar of students and young people considering pathways to employment.

7.4.2 Could employment service providers be further incentivised to assist jobseekers into the sector?

In addition to smaller tailored programs, mainstream employment service programs – Disability Employment Services (DES), Workforce Australia and, in remote locations, the Community Development Program (CDP) – have an important role in guiding unemployed jobseekers to take up opportunities in the care and support sector. These jobseekers have often been out of work for some time or face multiple employment challenges.

Employment service providers are paid outcome payments when they place a jobseeker into a job for a period (typically at 4-weeks, 12-weeks and 26-weeks). The value of outcome payments increases the longer a jobseeker remains employed.

The nature of many care and support sector jobs – sometimes characterised by low, variable hours and casual jobs with high-turnover rates – could put outcome payments for employment service providers at risk. To some extent, this may provide a disincentive for employment service providers to place jobseekers into care and support jobs.

We note these incentives could be reviewed for the care and support sector, taking into account that any jobseeker referred to these roles should have the appropriate skills, values and attitudes.

7.4.3 Supporting the peer workforce

NDIS workers with disability – or 'peer workers' – are not well represented in the NDIS workforce. More must be done to increase the representation of people with disability in the NDIS workforce.[2114]

In addition to improving employment outcomes for people with disability, the workforce needs to grow to meet demand and improve quality by harnessing the untapped potential of people with disability.

The Joint Standing Committee on the NDIS heard workers with disability faced discrimination and challenges when trying to enter the workforce – this includes employers being unable to see past the disability, building accessibility issues and the misconception that employers will need to provide significant additional support.[2115]

The Joint Standing Committee on the NDIS recently outlined steps to help develop the peer workforce in the NDIS.

> *"The committee recommends the Australian Government implement a targeted strategy to improve employment opportunities for people with disability within the NDIS workforce specifically, that is co-designed by people with disability and peak bodies." – Joint Standing Committee on the NDIS*[2116]

In response, the Australian Government indicated that the NDIS Participant Employment Strategy 2019-2023 has a goal to enable 30 per cent of participants of working age to be in paid work by 2024.[2117] We support this ambition.

There are also some barriers to work that could be removed now. We note the 2020 Productivity Commission Mental Health inquiry recommended removing barriers to work for Disability Support Pension (DSP) recipients.[2118]

Under the current criteria, DSP recipients may lose eligibility for the DSP (and any additional concessions they were eligible for) after a sustained period of employment of 30 or more hours per week. This can put up a barrier to recipients working additional hours of work. The Productivity Commission recommended the weekly hour limit be increased to 38 full time hours per week (to match the ordinary hours of work in the National Employment Standards).

The Australian Government is also undertaking a pilot program that would trial an employment concierge within the NDIA for people with disability in the NDIS.

From early 2023, the concierge would provide expert advice and a supporting hand to people who want to work. NDIS participants who have an employment goal will be supported to engage with a Disability Employment Services (DES) provider and to coordinate the support they receive through both NDIS and DES.

Where these participants choose to work in the NDIS, it will further support the valuable work a peer workforce would provide to participants. The concierge program should be evaluated, with people with disability to assess its impact.

Box 86: More focus on peer workers in the disability sector will improve the quality of support provided

There is much the disability sector could and should learn from the mental health sector, where peer workers are much more widespread. Any barriers to the employment of peer workers with a disability should be considered as part the unified Disability Employment Strategy (see Action 1.7).

Building the peer workforce should start with increased support for individual and family capacity building being delivered by peer workers as part of the increased investment in foundational supports (see Recommendation 1).

7.4.4 Targeted migration can help fill acute workforce gaps

Migration can play a role in supplementing the domestic care and support workforce, where gaps are not able to be filled by domestic workers in the short-term. In 2021, 2 in 5 workers in the care and support workforce were born overseas (compared to around 1 in 3 in the overall workforce).[2119]

Some roles in the care and support sector (including allied health professionals and other highly -skilled workers) qualify for skilled migration. Migration pathways are more limited for personal care and support workers.

As noted above, the expected shortfall of workers across the sector are concentrated in the occupation groups Aged and Disabled Carers and Nursing Support and Personal Care Workers. Some recent changes have provided targeted options for lower skilled workers to help with acute gaps, including training for 500 Pacific Australia Labour Mobility (PALM) scheme participants to complete their Certificate III in Individual Support (Ageing) in 2023 while they work for up to four years in Australia.

Additional effort and initiatives could be used to address short-term acute workforce gaps across the NDIS and broader care and support sector.

Industry labour agreements can potentially offer a flexible pathway that can be responsive to labour market conditions and limited to workers with suitable skills, values and attitudes.

From May 2023, aged care providers have been able to enter into an industry labour agreement to streamline the recruitment of overseas direct care workers (see Box 87). These arrangements could be extended across the broader care and support sector facing similar workforce shortages. To attract migrant workers with the skills, values and attitudes that meet local demands, streamlined pathways to permanent residency should also be considered as part of the industry labour agreement, similar to that already available through the Aged Care Industry Labour Agreement (see Box 87).

Importantly, industry labour agreements should be responsive to changes in labour market conditions. These arrangements should be reviewed after a five year period and could include minimum language proficiencies and labour market testing requirements.

Box 87: New Aged Care Industry Labour Agreement

Under the Agreement, aged care providers can access streamlined visa nomination and processing as well as concessions to the skills visa requirements when recruiting direct care workers.[2120]

The aged care provider must agree to a Memorandum of Understanding with the relevant industry union(s) and can sponsor overseas workers for the:

- temporary Skill Shortage (subclass 482) visa in direct care occupations or

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- permanent residence under the Employer Nomination Scheme (subclass 186) visa program. In this case, workers must have at least two years of full time work experience in Australia in a relevant direct care occupation (usually three years of full time work experience is required).[2121]

While workers are still required to hold a relevant Certificate III (or equivalent) or higher qualification, concessions to the skills visa requirements also include: no requirement for post qualification work experience; English language concessions for workers with relevant community language skills; and lower annual salary (however, annual salaries must be of at least $51,222 or, if higher, the Annual Market Salary Rate).[2122]

These efforts should also not replace effective workforce planning.

The Panel for the *Review of the Migration System* recognised the while there is growing labour needs in some lower paying sectors that may not be able to be fully met from within the domestic workforce – particularly in the care sector – there are complex challenges with lower skilled and lower paid migration.

> *"Where skills gaps persist over the long term, or where the shortage relates to lower paid roles, the use of migration (particularly temporary) as a lever to alleviate shortages should be considered carefully. Sector-specific, as against economy-wide, shortages can persist due to a lack of capital investment or poor wages and working conditions in the sector. In such situations, alternative policy levers may be more appropriate or effective, either alone or in conjunction with migration." – Parkinson, Howe and Azarias[2123]*

We have recommended governments work together to develop targeted policy responses to workforce challenges across the sector (see Action 15.3). We also have a number of recommendations to reform the scheme rules and procedures (including pricing and payment approaches) to support a responsive and capable workforce.

The Australian Government has released for discussion an outline of its Migration Strategy highlighting the need to build a new temporary skilled migration system by, among other things, "… creating proper, tripartite, regulated pathways for desperately needed workers, recognising the long-term labour shortages in our essential industries like the care sector".[2124] The final Migration Strategy is expected to be released by the end of 2023.[2125] Reforms to migration pathways for care and support workers would need to align with the outcomes of this final strategy.

Action 15.2: The <u>Australian Government</u> should develop targeted and flexible migration pathways for care and support workers

This could include developing an industry labour agreement for the broader care and support sector targeted at workers who would not otherwise qualify for skilled migration. This industry labour agreement should be developed in consultation with industry and relevant employer associations and unions.

Implementation detail:

- This agreement should also consider appropriate requirements to attract migrants with suitable skills, values and attitudes. This could include minimum skills and language requirements. A streamlined pathway to permanent residency should also be considered.
- The agreement should be reviewed within five years to ensure it is flexible and responsive to changing labour market conditions.

7.5.   Better sector-wide workforce planning

Continuing down the path of focusing on a one-off sector workforce strategy is unlikely to result in workforce planning that is responsive to changing labour market conditions. It is also unlikely to deliver the joined-up approaches needed to enjoy the benefits of sector wide initiatives.

For governments to realise the dividends of the Review's proposed new sector level approaches (for example, improving and streamlining worker screening processes for care and support workers, see Action 17.5), ongoing governance and accountability is needed to ensure an integrated approach is lasting and fit for purpose.

This governance role should include responsibility for:

- overseeing workforce planning, including developing a data strategy – currently lacking for the care and support workforce. This would include working with Jobs and Skills Australia (JSA) in its role in analysing and reporting on emerging and future workforce, skills and training needs across the economy.
- coordinating targeted policy action and overseeing ongoing monitoring, evaluation and improvements. This should include overseeing the design, trial and evaluation of the workforce attraction and retention initiatives outlined (see Action 15.1).

The governance role would also complement the work of the newly established Jobs and Skills Councils (JSCs) in the VET sector. The dedicated JSC for the health and human services, early education, and sport, fitness and recreation sectors aims to provide industry with a stronger, more strategic voice in ensuring Australia's VET sector delivers stronger outcomes for learners and employers.[2126] These JSCs have responsibility for identifying skills and workforce needs for their sectors, map career pathways across education sectors, develop VET training products, support

collaboration between industry and training providers to improve training and assessment practice, and act as a source of intelligence on issues affecting their industries.

The recently released *Draft National Strategy for the Care and Support Economy* has signalled taking steps to improve sector workforce planning and governance.

> *"Among these steps [to ensure sufficient workers and that those workers have suitable skills and training] will be the establishment of a governance function to coordinate workforce planning across the care and support economy. This includes leveraging the work of the relevant Jobs and Skills Council; developing and overseeing a data strategy; identifying workforce gaps and work across governments to develop targeted policy responses; monitoring and evaluating actions; and disseminating ongoing learnings. Consideration of migration pathways for lower-skilled workers will form part of the solution in the short term. This will be complemented by actions to make jobs in care and support more attractive as part of a longer-term approach to workforce shortages." – Care and Support Economy Taskforce*[2127]

Figure 159: A sector-wide approach to workforce planning is needed[2128]

Workforce Planning Cycle

Governance

Clear ongoing accountability across the NDIS, aged care and veterans' care sectors is needed. The Commonwealth, in partnership with states and territories, has an important role in ensuring barriers to workforce participation are removed and ensuring the policy environment sends consistent messages as to the value placed on types of work and associated quality, price and skills.

This governance structure should also oversee the ongoing monitoring, evaluation and improvements in care and economy workforce outcomes.

Collecting intel to understand drivers and forecast workforce gaps

A lack of disaggregated and high-quality data has made it difficult to develop an evidence-base for planning of training, employment support and migration policies.

Greater levels of granularity in occupation and industry disaggregation for the care and support workforce is important for workforce monitoring, planning and development, as well as job design, career progression, training investment and remuneration. (National Skills Commission, Care Workforce Labour Market Study)

The Australian Bureau of Statistics (ABS) is currently conducting a review of Australian and New Zealand Standard Classification of Occupations (ANZSCO) codes, which will be finalised by December 2024. The ABS has proposed retiring the current 'Aged or Disabled Carer' occupation and separating it into five occupations (including 'Disability Support Worker' and 'Residential Aged Care Worker'). This greater level of disaggregation will better reflect the varied roles within the care and support sector and support the availability of more granular workforce data.

In the meantime, **workforce data collection could be facilitated through building data infrastructure to strengthen data sharing or (if cost effective) through the expansion of the workforce census currently targeted to aged care providers.**

Targeted policy action

Including data-informed planning for formal training and traineeships and migration

Informing user-orientated information for workers, employment service providers and training organisations

Several government agencies collect care and support market demand data but **information is not shared with industry and providers in a consolidated way, making it difficult to effectively operate and expand across programs** (NDIS National Workforce Plan: 2021-2025).

The **NDIS Demand Map** currently publishes interactive forecasts of NDIS workforce demand based on NDIS, Census and DSS data. There would be benefits from expanding the demand map to cover aged care and veterans' care supports. **A local footprint** can also assist in more effectively disseminating information. For example, the network of regional coordinators in DSS' Boosting the Local Care Workforce Program (BLCW) has played a role in delivering localised support to existing and prospective providers to plan for their workforce.

Reference text: National Skills Commission, Care Workforce Labour Market Study: Final Report, p. 47, September 2021; Australian Bureau of Statistics (ABS), ANZSCO Comprehensive Review: Preliminary Proposed Changes - Consultation Round 1, August 2023; DSS, NDIS National Workforce Plan: 2021-2025, June 2021.

7.5.1 Action & Implementation Details

Action 15.3: The <u>Australian Government</u> should develop an integrated approach to workforce development for the care and support sector

An ongoing governance function should be established to coordinate workforce planning and ensure the development of a sustainable care and support workforce.

This function should collaborate across the Australian Government, state and territory governments and have responsibility for:

- developing and overseeing a data strategy which incorporates data collection and demand and supply projections, which should be shared with industry to support providers, training organisations and workers to be responsive to changing market conditions
- identifying workforce gaps and work across governments to develop targeted policy responses and monitoring and evaluating actions and disseminating ongoing learnings.

7.6. Reforms to scheme rules and procedures are critical to supporting a responsive and capable workforce

7.6.1 Quality and safeguarding reforms for workers should balance improved safety outcomes for participants with steps to make it faster and simpler to join the sector

Workers are critical to the delivery of safe and quality supports. However, current safeguarding arrangements for workers are not working as well as they could.

As outlined in Chapter 5, worker screening is an important preventative safeguard to identify workers who may pose an unreasonable risk to participants, and therefore not be permitted to work in the NDIS. The effectiveness of worker screening, however, is limited by only being mandatory for those working for registered providers. Unregistered providers can opt-in for worker screening, and -self-managing and plan -managing participants can request their workers undergo worker screening. Despite this, only 6,467 of more than 154,000 unregistered providers have any workers with an NDIS Worker Screening Check as at 30 June 2023.[2129]

Improved worker screening requirements, accompanied by mandatory basic online training will help to ensure workers understand their obligations and do not pose an unreasonable risk of harm to participants. This should not result in an undue burden on workers (see Recommendation 17). Early in the Review, we recommended practical reforms to make worker screening faster, smoother and better harmonised across systems and jurisdictions (see Recommendation 17). Longer term, workers could potentially showcase their skills and qualifications through the worker screening database.

7.6.2 Reforms to support NDIS providers to build and retain a quality workforce

How and how much providers are paid has important flow on effects for attracting and retaining a quality workforce.

We have heard from some providers that they are unable to invest in the capability of their workforce under current pricing arrangements.

> *"There is a lack of correlation between the expectations of Commission and the Agency and the NDIA Disability Worker Costing model with regards to meetings, training and supervision of staff. The costing model assumes and allows for 8% of the hourly funding to meet these requirements, yet the Commission expects both generalised and client specific training, different models of supervision for clients that only have one support worker, care team meetings etc. Each staff member is also expected to have an individualised training plan, which in reality, we can't afford to individualise." – Employer, quoted in Health and Community Services Union, Australian Education Union, Multi-Employer Group[2130]*

> *"Training and development is harder to sustain yet the practice standards continue to require more particularly in the high intensity space and there is no funding to sustain this. Planning days for staff are no longer viable as any planning day for staff means there is not income received for that period of time." – Employer, quoted in Health and Community Services Union, Australian Education Union, Multi-Employer Group[2131]*

Feedback from providers in past reviews also suggested the NDIS pricing arrangements do not sufficiently allow for training and appropriate supervision.[2132]

This exacerbates workforce retention challenges.

In practice, training and supervision outcomes will depend on a range of factors including minimum training requirements, the level of enforcement, the level of information provided to participants on the 'quality' of supports provided, and the extent to which participants value this quality. Market conditions, including the level of competition in the sector and broader labour market tightness, will also shape training and other outcomes.

The introduction of the NDIS and the shift from a block-funded model to a competitive market-based model – where funding follows the participant and not the provider – not only increased demand for labour but also increased the casual workforce.

Casualisation increased from 36 per cent of all NDIS workers in 2016 to a high of 40 per cent in 2019.[2133] More recently, the rate of casual workers to permanent workers declined to 33 per cent in June 2021, increasing again to 37 per cent in June 2022.[2134] A small union-run survey of 25 employers found nearly three in four (73 per cent) had increased their casual workforce since the introduction of the NDIS.[2135]

Uncertainty in demand from participants and a fee-for-service payment approach is likely to have contributed to a greater use of casual work in the scheme.

"The numbers that are employed full time has significantly reduced as a result of the significant change to the types of services receive...This therefore has resulted in a large amount of uncertainty with stability to enable a large portion of full-time staff."
– Employer, quoted in Health and Community Services Union, Australian Education Union, Multi-Employer Group[2136]

"Our conversion of casual to PPT / FT [permanent part time / full time] has been very limited despite offers being made. The attraction of the higher casual rate has been a significant factor particularly when the cost of living becomes harder...It also needs to be recognized that as a provider it can be difficult to determine if work will continue to be ongoing, regular and systematic and to make a conversion this needs to be part of the determination." – Employer, quoted in Health and Community Services Union, Australian Education Union, Multi-Employer Group[2137]

"The 2022 Financial Benchmarking report shows high levels of casual employment for disability support workers. In our view this can only be because the pricing model incentivises this. Disability Support work is relational work, workers and people with disability alike want to build relationships, want predictability and stability in support. This cannot be best provided with a highly casualised workforce." – United Workers Union[2138]

The proposed reforms to the pricing and payment regulatory framework would help to ensure that the cost of maintaining a capable workforce, with appropriate supervision, and increased focus on quality and outcomes are better captured in pricing and payment arrangements. This includes:

- more transparent processes for setting price caps that reflect the market price for delivering supports (including any costs associated with regulation) with more robust information on the actual cost of delivering support and how much participants are being charged
- price caps that better reflect differences in the costs of delivering certain types of support – including, where appropriate, the cost of higher skilled workers delivering supports to participants with more complex needs or in higher cost locations
- shifting away from fee-for-service to other payment models that better focus providers on outcomes rather than outputs. Under the proposed enrolment payment approach for 24/7 shared living supports, providers would have greater stability of funding, supporting a more stable workforce that is familiar with the needs and preferences of the people they support. Providers may also invest more in labour-saving equipment for their workers, enabling workers to spend more time delivering the support that matters most to participants.

For First Nations and remote communities, under the proposed roll-out of alternative commissioning, participants may be better able to access supports where they live from people who are part of their community instead of having to rely on people who travel in and out of the community (see Recommendation 14).

Combined with reforms to focus on continuous quality improvement and information on provider performance (see Recommendation 12), these reforms would encourage providers to maintain a workforce capable of delivering safe and quality supports.

7.6.3 A focus on early intervention, capacity building and inclusion would relieve pressure on the workforce and help participant to live an ordinary life

A number of our reforms would support participants to be more connected to their community and reduce reliance on ongoing formal supports delivered by workers. These include early intervention supports for psychosocial disability (see Recommendation 7), and improved uptake in assistive technology and home modification supports including improved access to home modifications for participants living in social housing (see Recommendation 9).

This in turn would reduce future workforce pressure in the scheme. For example, the preliminary results of a recent study of 15 people with disability with complex support needs found that, after 6-24 months of living in Specialist Disability Accommodation with appropriate assistive technology, there was an average decrease of 2.4 support hours per participant per day 6-24 months following their move to the new arrangements.[2139]

Other reforms – such as, those which focus on better reflecting the costs of delivering supports and improving incentives to deliver supports in group settings (see Recommendation 11) – will also help build workforce capacity and capability while supporting participants to be connected and included in their communities.

Chapter 5: Quality and safeguards

6. Effective quality and safeguarding institutions and architecture across the full disability ecosystem

1. Key messages

- All people have the right to be safe. For people with disability, this right is enshrined in and reinforced by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) but is not always realised. Experiences shared with this Review and previous reviews and inquiries, including the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission), demonstrate very significant shortcomings in the current approach.

- Quality and safeguarding are critical to the success of the NDIS. It requires not only protecting against harm and bad outcomes, but also encouraging the delivery of high quality supports and empowering participants to achieve good outcomes.

- The NDIS has a responsibility to support participants to be safe and prevent harm to those most at risk. However, this responsibility must be balanced with empowering participants to exercise their choice and control and engage in the dignity of risk. It must also ensure an environment in which NDIS markets can thrive and innovate and empower participants with choices of quality supports that achieve good outcomes.

- Quality and safeguarding have many dimensions, which means there are no simple solutions to achieve this balance. Risk, safety and quality look different for every participant, requiring approaches that account for individual circumstances. At the same time, effort should be applied at the system-level to strengthen the capacity of participants to safeguard themselves and develop their natural safeguards, reduce unacceptable risks of harm, and drive improvements in the quality of supports. Everyone has a role to play in supporting and empowering participants, requiring coordination and collaboration across all government and non-government actors.

- We have identified five key areas of reform to shift the dial on quality and safeguarding. Implementing reforms to quality and safeguarding will require sustained effort over a number of years, moving with urgency to address most significant areas of risk. This is likely to require a prioritised and sequenced approach, including taking account of recommendations made by the Disability Royal Commission.

Safeguarding that is empowering and tailored to individuals, their service needs and environments

- The NDIS needs to do more to support and empower participants to be safe in a way that recognises and responds to their individual circumstances. Safeguarding strategies that are centred on and owned by participants will be most effective. To date, the NDIS has not always effectively and proactively engaged with participants about the risks they face and the support they need to be safe. Participants have not been supported to build their capacity, strengthen their natural safeguards or access additional safeguards that are tailored to their needs.

- Reform is required to proactively engage with participants about risk and safety. This requires safeguards that are tailored to individual circumstances and are developmental, so as to build the capacity of participants to identify unwanted risks and safeguard themselves. In addition,

the NDIS and other systems must work together to support the safety of people with disability, and in particular those facing higher risks or with more limited natural safeguards.

A new risk-proportionate model for regulation of providers and workers

- Alongside efforts at the individual level to better empower participants to be safe, a more risk-proportionate approach at the system-level to the regulation of providers and workers is required. This is necessary to better prevent harm while continuing to support choice and control and enable a thriving market. To date, regulation has not been sufficiently proportionate to the risk of supports. This has led to both gaps in regulatory oversight for some (particularly higher-risk) supports, as well as excessive burdens for lower-risk supports. In many cases, providers can opt out of most regulation, which places an inappropriate burden on participants to manage risk themselves.

- Reform is required to deliver a new graduated and risk-proportionate regulatory model for the regulation of providers, striking the right balance of regulatory oversight of the whole market without imposing disproportionate burden. This should be supported by improved safeguarding requirements for workers, and regulatory responses to emerging and long-standing safeguarding issues.

Continuous quality improvement

- Driving continuous improvement in the quality of supports, providers and workers is critical to the NDIS achieving good outcomes for participants. Quality and safety are interconnected, and the NDIS must drive improvements in both. To date, efforts have rightfully prioritised safeguarding in establishing national regulatory requirements, in part due to limited resourcing in the regulator. However, this has led to a lack of focus on quality improvement by the regulator and many providers.

- Reform is required to elevate the regulator's focus on driving quality through a dedicated and well-resourced quality function; enhance capacity-building, outreach and auditing to strengthen understanding of what good quality looks like and focus on improving quality; and sharpen incentives for quality improvement through improved transparency about the quality of supports.

Reduction and elimination in the use of restrictive practices

- Efforts to reduce and eliminate restrictive practices need to be urgently reinvigorated, with a joint focus by all Australian governments on Australia's commitments under the UNCRPD. Guided by the UNCRPD, all Australian governments should develop a collaborative approach to regulation of restrictive practice that focuses on reducing and eliminating their use, not only their authorisation. To date, restrictive practices have continued to be used against people with disability, including in the NDIS. Actions by governments have not been sufficiently effective or coordinated, with differences in requirements, a lack of information sharing and insufficient corrective action. The quality of behaviour support plans is generally low, and providers need to improve their approaches.

- Reform is required to urgently reduce and eliminate restrictive practices. Governments should work collaboratively and proactively, including to impose consequences for providers. Governments must also drive efforts to improve the quality and accessibility of behaviour support planning, and support providers in delivering on their important role.

Effective quality and safeguarding institutions and architecture across the full disability ecosystem

- Getting supporting architecture and institutions right is critical to improving quality and safeguarding efforts. Delivering on the ambitions set out in our recommendations will require all parts of government to be operating effectively and in a much more coordinated way. To date, many of the challenges experienced in relation to quality and safeguarding highlight a lack of strategy, coordination and accountability across all parts of the system. Reform is required to ensure clear direction and accountabilities for quality and safeguarding, along with better coordination and information sharing amongst all players in the system. All barriers to timely and effective information sharing between regulators should be removed as a matter of urgency.
- There are also opportunities to drive more consistency in regulation, including by bringing together regulation for all Australian Government funded disability supports under an expanded National Disability Supports Quality and Safeguards Commission. This should involve investing in improvements to the culture, capability, posture and engagement of the regulator to deliver a more proactive, responsive and risk-based approach using the full range of its regulatory levers.

Box 88: Key Concepts

The 2016 NDIS Quality and Safeguarding Framework (the Framework) describes an overarching architecture and specific initiatives to make NDIS supports safe and good quality. While there has been positive progress in implementing parts of the Framework, other parts have not been implemented as envisioned. The Framework is also out of date, as it was developed for the transition to the full NDIS.[2140]

Regulation can be both *formal* and *informal*. Formal regulation includes things like rules and standards. Informal regulation includes things like community attitudes and expectations. Formal and informal regulation complement each other. This is because people are more likely to follow the rules if the community expects them to and will hold them to account if they do not.[2141]

Safeguards are "actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives".[2142] Safeguards can be both formal and natural, and can be categorised as developmental, preventative and corrective.

Formal safeguards are rules and actions that are taken by organisations with formal responsibility for the safety of people with disability.[2143] In the NDIS, these include rules that

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providers and workers must follow, and other supports such as advocacy, visitation and outreach, and support coordination.

Natural safeguards (also called informal safeguards) are actions and features that are part of people's day-to-day lives and support them to manage their safety.[2144] In the NDIS, these include the skills, confidence and support from family, friends and community for people with disability to speak up if they are unhappy with a support or service.

Developmental safeguards are measures that strengthen the capability of people with disability, their families and supporters, and providers and workers to reduce the risk of harm and promote quality.[2145] In the NDIS, these include engagement and education activities for people with disability and their supporters, training for workers on working with people with disability, and information for providers on how to deliver quality services.

Preventative safeguards are measures that proactively regulate providers and workers to reduce the risk of harm and promote quality.[2146] In the NDIS, these include provider registration and audits, standards for quality services, and worker screening.

Corrective safeguards are measures that resolve problems, enable improvements to be identified and avoid the same problems recurring. [2147] In the NDIS, these include the NDIS Quality and Safeguards Commission's complaints and reportable incidents functions, and its ability to investigate issues and take compliance action in response to breaches of requirements.

2. Safeguarding that is empowering and tailored to individuals, their service needs and environments

- Current approaches to safeguarding in the NDIS do not effectively engage with participants to understand their unique circumstances, perspectives and experiences of risk and safety; nor to implement safeguarding strategies that are tailored to their needs and circumstances. They are also not well integrated or coordinated with safeguarding efforts outside the NDIS.
- While preventative and corrective measures are available to respond to problems, there are not enough developmental measures available to empower participants and their supporters to play an active role in managing risks, and to give participants and their supporters the tools they need to do so.
- To address these concerns, a refreshed safeguarding approach is needed that empowers people using disability supports in the NDIS with safeguards that are tailored to their individual circumstances, to both prevent bad things from happening and ensure that good things do happen. An empowering and individualised approach to building safeguards will better recognise and respond to the circumstances of all people with disability, and in particular those facing intersectional discrimination and inequality, such as First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities.
- Safeguarding efforts should prioritise building capacity, natural safeguards and community connections. This should be balanced with targeted, more intensive options for people in

circumstances that place them at particular risk of harm or with more limited natural safeguards. The NDIS should also work with, and connect participants to, other systems that can help with more intensive support, such as state and territory-operated Community Visitor Schemes and adult safeguarding agencies.

- These reforms will take time to implement and require close cooperation across different levels of government. A shared strategy and approach across governments will ensure that all government agencies are clear on their roles and responsibilities, and that people with disability know where to go to seek assistance and receive joined-up support. However, there are steps that can be taken now to improve the wellbeing of people with disability and support them to build and strengthen natural safeguards.

Recommendation 16: Deliver safeguarding that is empowering and tailored to individuals, their service needs and environments

🗐 Legislative change required

- Action 16.1: The Disability Reform Ministerial Council should agree a Disability Support Ecosystem Safeguarding Strategy to coordinate activities to support the safeguarding of people with disability.
- 🗐 Action 16.2: The National Disability Insurance Agency should design, pilot and implement a new individual risk assessment and safeguard building process.
- Action 16.3: The Department of Social Services, working with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and other agencies where relevant, should ensure participants can consider and access a wider range of safeguarding supports.
- 🗐 Action 16.4: State and territory governments, with support from the Department of Social Services, should ensure participants can access high-quality, nationally consistent Community Visitor Scheme offerings that interface with the NDIS.
- 🗐 Action 16.5: State and territory governments should establish or improve adult safeguarding agencies to deliver a universal service offering for the safeguarding of all people at risk of harm, including people with disability.

2.1. Safeguarding approaches in the NDIS lack clear roles, are not well coordinated and are too narrowly focused on NDIS agencies

The National Disability Insurance Agency (NDIA) and NDIS Quality and Safeguards Commission (NDIS Commission) have a range of different strategies for supporting participants with safeguarding measures. These strategies are not well coordinated, nor well-integrated with safeguarding efforts outside the NDIS. This has resulted in both overlapping initiatives and gaps, instead of a coordinated and clear system for meeting the needs of people with disability (including participants) when they face risks.

A reinvigorated approach guided by a clear strategy setting out roles and responsibilities for different agencies will help government agencies, people with disability and their supporters, and providers to better understand the different roles and responsibilities for safeguarding in the NDIS.

2.1.1. Strategy and responsibilities in NDIS safeguarding are not clear for participants or the government agencies implementing them

People with disability have a right to be safe from violence, abuse, neglect and exploitation, including when they participate in the NDIS. The NDIA and NDIS Commission both have responsibilities to work with participants to support them with effective safeguards, and enable them to take appropriate, informed risks (commonly referred to as the 'dignity of risk'). These responsibilities arise from, and are reinforced by, Australia's international obligations, including obligations to all people with disability under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).[2148]

To deliver on these responsibilities, the NDIA and NDIS Commission have developed a range of strategies, policies and approaches to help participants manage risks and support them with safeguards. This includes recent positive developments such as the NDIA's Participant Safeguarding and Supported Decision-Making Policies.[2149]

However, these policies and approaches have tended to focus on what each individual agency can do, and their preferred approaches, rather than considering how the system as a whole should work together to assist participants with risk. For example, while the NDIS Commission contributed to the development of the NDIA's Participant Safeguarding Policy, the priorities outlined in the Policy focus on the NDIA's activities. This has meant it is not always clear for participants what options they have to seek support and who is best placed to provide that support. Equally, it is not always clear for agencies what role they should be playing and how that relates to the roles of other agencies.

> *"Many roles under the NDIS can be confusing for participants, supporters and providers alike. For instance, the difference between the roles and functions of the National Disability Insurance Agency (NDIA) and the NDIS Commission is not well understood" – People with Disability Australia[2150]*

> *"RHC strongly encourages a holistic approach to both regulatory and non-regulatory safeguards to ensure the underlying policy objectives are achieved. It is evident there are clear linkages with health, aged care, and education… These safeguards must be fit-for-purpose and flexible whilst taking into consideration individuals differing capabilities, circumstances, and the environment" – Ramsay Health Care[2151]*

The development of the 2016 NDIS Quality and Safeguarding Framework (the Framework) was intended to provide an overarching strategy and clear roles for safeguarding across the NDIS. [2152] However, the Framework has not successfully promoted coordination amongst the multiple governments and agencies involved in the NDIS and their respective policies and initiatives, as well as the wider system of safeguarding initiatives. Participants continue to struggle to identify the best

service or agency to help them with the risks they face. For example, we have heard that participants have limited information about mainstream services that could help them with the risks they face, and that as a result participants often go to the NDIS Commission or NDIA before being referred to other agencies for assistance.[2153]

The Framework also takes too narrow a view, focusing on quality and safeguarding for NDIS supports without addressing the broader disability support ecosystem. We are recommending that the Framework be expanded to cover quality and safeguarding for the full disability support ecosystem, which will provide clarity and coordination in the range of safeguarding supports available for people with disability. The role and implementation of the Framework is discussed in more detail in Section 6.1.1 and Action 19.1.

We have also heard strongly that the NDIA and the NDIS Commission cannot and should not be responsible for every safeguard for people with disability,[2154] especially when people with disability experience higher rates of issues that the NDIS alone cannot address (for example, experiences of violence or economic disadvantage).[2155]

Instead, the roles of the NDIA and NDIS Commission need to be clear and obvious. They must work closely with other parts of government, providers, the regulators of other services used by people with disability, and most importantly participants themselves to help participants to be safe. Where other safeguarding agencies are better placed to respond to a particular risk (for example, Community Visitor Schemes or Adult Safeguarding Agencies – see Actions 16.4 and 16.5), participants should be supported to engage with them and NDIS agencies should recognise the valuable role they can play in helping participants.

Finally, we note the particular risk and safeguarding challenges posed by natural disasters like floods, fires and pandemics. Natural disasters and emergencies are well recognised as a risk factor that is exacerbated for people with disability.[2156] In response, agencies like the NDIS Commission and the NDIA have already taken steps to ensure providers are prepared to plan for and support people with disability during emergencies and disasters.[2157]

However, natural disasters often require a whole of community response led by mainstream agencies like emergency services. As a result, better coordination and information sharing between disability support safeguarding systems and wider emergency responses will help people with disability to be better prepared for and supported through natural disasters.

2.1.2. There is an opportunity to clarify the strategic approach and roles and responsibilities of agencies so participants receive better support

In response to the challenges described above, as part of our 'Participant Safeguarding Proposals Paper' released in May 2023, we proposed the development of a new NDIS-wide Participant Safeguarding Strategy to coordinate the roles and responsibilities of different government agencies in safeguarding participants. This would give participants and agencies clarity around what role different agencies play and how they work together.[2158]

Feedback we received was generally supportive of more coordination and accountability for the actions of different agencies. Some submissions suggested that the proposed Strategy needed to provide clarity for particular groups, including outlining provider and worker responsibilities around participant safeguards, and reflecting agreed approaches to respond to child safety issues. Others raised the role that other systems could play in helping participants to be safe and exercise their rights, such as consumer and work health and safety laws and regulators. These systems and their intersections with the NDIS are discussed in Section 3.3.1 and Action 17.6.

> *"[I]t is crucial that the strategy is consistent with the expectations set by the [NDIS Quality & Safeguarding] Framework for workers and providers. Often these expectations are not well understood by government agencies which can result in misperceptions about the role of providers and workers within the NDIS" – National Disability Services[2159]*

> *"Any strategy must also expressly address cohorts of child participants at heightened risk of experiencing abuse and neglect. These include child participants involved with Child Protection" – Victorian Commissioner for Children and Young People[2160]*

More clarity is needed around the responsibilities of everyone involved in upholding the rights of people with disability and supporting them to be safe. This should include all people with disability and the supports they access, not just participants, to ensure that safeguarding approaches are well coordinated across the full disability support ecosystem.

Providing this clarity and having measurable outcomes that can hold everyone to account will ensure that people with disability and their supporters know where to go to seek support when issues arise, and receive appropriate support when they need it. This approach will ensure that governments can build on the positive work undertaken by the NDIA and NDIS Commission to clarify their distinct roles and enable them to collaborate more effectively, such as in their agreement on a shared approach to escalating risk responses developed following the death of Ms Ann-Marie Smith.[2161] It will also support the delivery of the enhanced and personalised approaches to safeguarding described in Actions 16.2 and 16.3, and ensure the state and territory mechanisms described in Actions 16.4 and 16.5 are leveraged effectively in combination with disability-specific measures. It should also drive stronger connections with safeguarding across the broader disability support ecosystem and in mainstream services.

We believe these aims are best achieved through the development of a Disability Support Ecosystem Safeguarding Strategy, covering safeguarding across all disability supports provided through the NDIS and foundational supports, and with strong connections to safeguarding in mainstream service systems.

The broader scope than initially proposed in our May 2023 'Participant Safeguarding Proposals Paper' reflects the importance of a well-coordinated and consistent approach to safeguarding for people with disability accessing support. The development of such a strategy will ensure that all people with disability accessing the support they need can do so with clear and accessible safeguards, and with everyone across the disability ecosystem working together effectively to support their safety.

2.1.3. Action & Implementation Details

Action 16.1: The <u>Disability Reform Ministerial Council</u> should agree a Disability Support Ecosystem Safeguarding Strategy to coordinate activities to support the safeguarding of people with disability

This should ensure clarity about strategy, coordination and responsibilities across government agencies, and connections with broader safeguarding arrangements (see Actions 16.4. and 16.5). It should sit under the new Disability Supports Quality and Safeguarding Framework (see Action 19.1) and operationalise a more coordinated approach to safeguarding across the disability support ecosystem (including foundational supports), with strong connections to safeguarding in and regulators of mainstream services.

- The Department of Social Services should lead the development of the Strategy in partnership with the NDIA, the new National Disability Supports Quality and Safeguards Commission and state and territory agencies; and with strong engagement with people with disability. The Strategy should include the following features:

  - Sit under the new Disability Supports Quality and Safeguarding Framework (see Action 19.1).

  - Clarify and coordinate the roles and responsibilities of all government agencies in safeguarding people with disability, including by setting the measurable outcomes to be delivered. This should include clarifying and emphasising connections with groups and agencies that respond specifically to the issues faced by people facing intersectional discrimination and inequality.

  - Support effective safeguarding coordination and interfaces across the disability support ecosystem (that is, both the NDIS and foundational supports), with related safeguarding arrangements such as Community Visitor Schemes and adult safeguarding agencies (see Actions 16.4 and Actions 16.5), and with safeguarding in mainstream services.

  - Drive practical, meaningful improvements by identifying and directing action towards specific issues and harms. Particular focus should be given to improving coordination around particular risk factors and circumstances, such as natural disaster responses.

  - Be supported by performance monitoring and reporting as part of accountability measures for the Disability Supports Quality and Safeguarding Framework (see Action 19.1).

2.2. Participants are not being proactively engaged or empowered to be safe and get good outcomes with personalised safeguards

Risk and safety look different for everyone. The safeguards put in place in response to these issues cannot take a one-size fits all approach. However, the NDIS does not always effectively engage with participants about the risks they face and may even exacerbate these risks in the way participants can access some supports (such as through access to unregistered providers for high-risk supports). As a result, safeguarding approaches do not do enough to respond to the varying needs of, and risks faced by, participants.

To ensure safeguarding in the NDIS is effective, participants must be at the centre of their own safeguarding. This means that safeguarding efforts must operate at both the system-level and individual-level to support and empower participants to be safe. A refreshed NDIS safeguarding approach is needed to support participants to achieve the outcomes they want by recognising their individual circumstances and empowering them with the support they need to be safe and manage the risks they face.

2.2.1. Current approaches are reactive and do not effectively engage with participants to understand and address the risks they face

The NDIS has a range of mechanisms in place to monitor and respond to the safeguarding needs of participants. However, these mechanisms are typically reactive and do not necessarily respond to the specifics risks that participants are facing. Currently, the NDIA and NDIS Commission have several main tools and approaches to understand and respond to risk:

- **NDIA participant risk assessment:** Currently, the NDIA planning and assessment process is an opportunity to consider the risks and safeguards that a participant may need. Planners can use a range of mechanisms in response to the issues raised, including allocating funding, making referrals to safeguarding organisations, and organising check-ins where needed to monitor the participant's risk situation over time.[2162]
- **Participant check-in calls:** The NDIA calls some participants to discuss their current situation and check on participant wellbeing and plan arrangements.[2163]
- **Complaints, regulatory intelligence and enforcement:** The NDIS Commission has a range of powers it can use to respond to complaints from participants about the risks they face from provider or worker actions. For example, the NDIS Commission can apply banning orders or issue a compliance notice if a provider or worker fails to meet their obligations to the participant, or launch a more detailed investigation through their Own Motion Inquiry or site visit powers.[2164] However, these mechanisms rely on someone making a complaint about the service or issues being raised with the NDIS Commission in audits or through reportable incidents.
- **NDIS agency coordination and information sharing:** The NDIA and NDIS Commission have agreed an approach to helping participants in higher risk situations. Following the Robertson Review into the circumstances relating to the death of Ms Ann-Marie Smith, the two agencies agreed to streamline information sharing arrangements and develop a joint approach to

identifying and responding to participants at risk. This approach brings together the above mechanisms and describes how the two agencies coordinate their responses and share information in relation to the risk involved.[2165]

- **Information sharing with states and territories**: The NDIA and NDIS Commission also share information with state and territory agencies in some circumstances, including safeguarding agencies and emergency services. For example, the NDIS Commission has information sharing protocols with a range of state and territory agencies involved in safeguarding. They establish what information is generally shared between the agencies and why, but do not overrule legislative requirements.[2166]

However, these processes have not always been effective in practice. Participants have told us that they are often unaware of risk assessment processes, and that they have found the risk assessment and check-in calls confronting.[2167]

> *"[T]he way the questions [about risk in a planning meeting] were delivered was confronting, but what is more concerning is that the planners are not given any means to do anything with the information they collect. They aren't trained to establish a safe environment to ask the question..." – Participant submission to the Disability Royal Commission[2168]*

The motivations for check-in calls were sometimes confused with wellbeing checks, and in some cases resulted in plan funding reductions that participants did not expect.[2169] Complaint mechanisms and the enforcement action that follows them have also been criticised for being slow, inadequate and for not communicating progress with complainants.[2170]

These concerns demonstrate some of the challenges of the current, largely reactive, approach taken by NDIS agencies to respond to safeguarding issues. Agencies typically react to a risk having emerged for the participant, rather than taking a proactive approach to prevent it from occurring in the first place. This can mean that participants are unable to seek support with potential risks until they become active problems.

Previous reports have also highlighted that relying solely on reactive approaches depends on participants and their supporters raising issues.[2171] This means that the NDIS is not well positioned to anticipate situations where risk may increase (based on research, experience and regulatory intelligence) and cannot readily adapt safeguards to meet the changing needs of participants.

> *"[I]t is not up to individuals and their supports to enforce those safeguards. Despite all those supposedly existing safeguards, people like me are experiencing poor quality and unsafe services. And I worry a lot about what people with higher needs, not able to communicate for themselves, etc are experiencing" – Participant[2172]*

In addition, the approach currently taken by the NDIA and NDIS Commission does not do enough to recognise the different ways people experience and engage with risk. People with disability are members of diverse communities with a wide range of cultural and social determinants that inform differing conceptions of what safety means, and what level of risk they want to engage with

(referred to as the 'dignity of risk').[2173] As a result, safeguarding is inherently personal and varies depending on the person and their community, meaning they are best placed to make decisions about what they need to be safe and manage risks.

Similarly, sometimes participants may experience risks that are not well recognised by NDIS agencies as a risk to their safety, like the sudden absence of suitable services for participants to use to meet their day to day needs (for example, an illness affecting a support worker who helps someone safely get out of bed).[2174] Some of these risks have been exacerbated by the individualised nature of the NDIS, which can mean that no one has an overarching responsibility to coordinate supports or an overarching duty of care.

> *"The one-size-fits-all approach fails to meet the diverse needs of participants, including LGBTQIA+ participants. The limitations of the current NDIS model also become apparent when it comes to cultural sensitivity and understanding. Many participants, including our LGBTQIA+ NDIS clients, face difficulties in finding planners and service providers who possess the necessary knowledge and empathy to address their unique identities and experiences" – Wide Bay Advocacy[2175]*

The NDIA has set out some positive ambitions for addressing concerns about risk and safeguarding processes being too reactive and insufficiently tailored to individual circumstances through the development of a new Participant Safeguarding Policy.[2176] Key improvements proposed in the policy include a more individualised approach to identifying and responding to risks, and identifying the need to develop strong natural safeguards.

However, in practice, participants are still not sufficiently engaged in determining how to respond to risk and are not true partners in this process. More work is also needed to develop the safeguards required to operationalise the policy. We see opportunities to build on the ambitions set out in the NDIA's policy.

2.2.2. There are limited safeguarding options available to support participants and insufficient focus on developing participant capacity to manage risk

Participants already have access to a range of safeguards through their own communities, the NDIS Commission and other government agencies. However, these safeguards often do not address the specific problems or risks individual participants face when accessing supports, nor do they build participant capacity or natural safeguards to manage these risks. Given the majority of adult participants have a cognitive disability, many would benefit from support for decision-making. In addition, around 50 per cent of participants are children or adolescents and may require additional support.[2177] The NDIS must provide a range of capacity building safeguards to help participants make or be supported to make decisions and manage the risks they face.

The 2016 NDIS Quality and Safeguarding Framework envisioned a balanced mix of developmental, preventative and corrective safeguards. In response, the NDIS Commission has developed important preventative and corrective mechanisms, such as provider registration, worker screening and complaints processes, to ensure providers and workers comply with relevant rules and standards.

However, as the NDIS has rolled out, the focus has almost exclusively been on regulatory arrangements, with insufficient attention given to developmental supports. Numerous reports and stakeholders have identified that developmental supports such as capacity building and support to strengthen natural safeguards have been slow to emerge.[2178]

> "Information about people's rights and entitlements, skills and confidence in advocating need to be considered as life skills. For some people support in exercising choice and decision is also essential, as are building the capacity of carers, families and friends, and supporting people to establish and create connections, and to be informed of and be able to access independent advocacy." – Participant[2179]

Using a model like the Model of Citizenhood Support (see Box 89), we can understand the varying levels of personal resources that a participant has available to advocate for their rights.[2180] This can help to identify where participants are at higher risk, or where they may need more help to build their personal capacity or strengthen their natural safeguards. This may be because of their environment (for example, an isolated setting or a lack of natural safeguards), the types of supports they receive, having lower levels of capital to start with, or systemic issues such as discrimination and inequality or a failure to consider and respond to cultural concepts of disability and care.

In these situations, more intensive support is needed to ensure that participants who need assistance to build capacity and natural safeguards get the support they need – as well as more targeted responses to higher risks. As noted above, the current approach does not offer sufficient developmental safeguard options to be able to effectively help participants to build their capacity; nor does it do enough to intervene with more intensive and formal safeguards (such as independent advocacy and outreach through Community Visitor Schemes) in response to higher risks.

Box 89: The Model of Citizenhood Support – identifying personal resources to help manage risk

The Model of Citizenhood Support identifies four main 'capitals', or "areas of capacity and growth".[2181] This approach can help understand where an individual may need to build or strengthen their safeguards. The four capitals are:

- **Personal Capital** – the personal resources, strength and resilience to represent themselves (for example, the ability to self-advocate).
- **Knowledge Capital** – the skills and ability to use knowledge for actions (for example, access to information).
- **Material Capital** – resources and material goods (for example, income and community resources).
- **Social Capital** – relationships and connections (for example, family, friends and community).

2.2.3. An improved approach is needed to engage with and support participants to manage the risks they face

Participants will be most effectively supported by a system that recognises that risk and safety look different for every person, and that helps participants to exercise choice and control and manage risks. Such a system should support participants with a range of empowering safeguards to build their capacity to manage the risks they face, and then offer more intensive safeguards when they are experiencing higher risks.[2182] The system should be person-centred, where safeguards and supports are focused on listening to the participant's perspective and ideas on what they need to be safe and engage with risk.[2183] As risks can arise anywhere, not just when someone receives NDIS-funded supports, responses to these risks should recognise and respond to this by building participant capacity to be safe and exercise their rights in all situations.[2184]

> *"We continue to advocate that the best tool we can use to safeguard a person living with disability is to support them to take up their rightful place at the heart of their community." – JFA Purple Orange submission to the Joint Standing Committee on the NDIS inquiry into the NDIS Commission[2185]*

To work towards this kind of system, we identified and sought feedback on two broad ideas for change in our May 2023 'Participant Safeguarding Proposals Paper'.

Risk assessment and safeguard building process

The first idea was the creation of an individualised, participant-led approach to understand risk and build safeguards. This would take the form of conversations with participants and their supporters about risk and safeguarding, including identifying appropriate safeguarding options to manage the risks that a participant is facing. It would also involve agreeing a way to monitor and review the outcomes of the risk assessment to ensure participants have the support they need to manage risk if their circumstances change.[2186] This would build on the positive ambitions set out in the NDIA's Participant Safeguarding Policy and the NDIA and NDIS Commission's joint approach to identifying and supporting participants at risk, by further strengthening efforts to build a more proactive and individualised approach to identifying, assessing and managing risks.[2187]

We received many submissions in relation to this proposal. Responses generally supported the idea of a participant-led approach to assessing risk and ongoing monitoring. Some submissions proposed the use of a care plan or similar document to record and monitor the outcomes of the process, while others emphasised the need for the record to be easily accessible.[2188] Respondents emphasised the importance of trusted relationships in having these conversations, and generally supported an approach where participants could choose who they discuss risk concepts with. They also suggested assessments could be updated as a participant's situation changes (for example, when reaching a key life milestone).

> *"Where necessary additional support outside of NDIA staff will need to be available to enhance planning and supported decision making. As noted in the Paper some*

participants will require time to build a trusted relationship with a person to support them to have meaningful conversations about risk" – National Disability Services[2189]

"Develop specific strategies to empower and support children with disabilities to share their own views on the risks to safety they face, their safety priorities, and the supports they need... Provide training to families and service providers in recognising signs of risks and harm in children and young people with disability" – KIIND[2190]

Taking this feedback into account, we are recommending the development of a proactive risk assessment and safeguard building process that will better support participants to manage risks. This process should be integrated into the recommended participant pathway, and in particular into the assessment of need and budget setting process (see Recommendation 3). It could also provide an opportunity to identify the potential need for a behaviour support plan (see Section 5.2.3 and Action 18.2).

This process should involve a number of steps to help a participant to identify, respond to and then monitor risk in their lives (as depicted in Figure 160):

- Prior to the needs assessment, participants should be supported with resources to help them have discussions about risk with a trusted person in their life. They should be able to use this discussion to develop a self-report to provide to their needs assessor.
- During the needs assessment, the participant should be supported to lead a conversation about risk and what responses can be put in place. The assessor should ask questions where needed and draw on the information the participant has already provided to avoid the need to repeat details.
- Following the risk assessment, the outcomes of the assessment should be recorded in an accessible format as part of the wider needs assessment outcomes. These outcomes should be used to inform the budget setting process where supports necessary for safety should be funded through individual reasonable and necessary budgets.
- Navigators should then work with participants to identify, connect and refer them to appropriate services and safeguards as part of the participant's plan of action.
- Over time, the risk assessment and effectiveness of safeguards put in place should be monitored and reviewed. Monitoring and review strategies should enable changes in participants' circumstances to be recognised, and should lead to the development of a revised assessment where needed.
- Navigators should identify and help participants to respond to risks over time, and should refer them to other agencies for further support where needed (such as state and territory Community Visitor Schemes and adult safeguarding agencies).
- Agencies should also share information seamlessly (in line with improved information sharing arrangements (see Action 19.2) and with all necessary participant consent sought during the initial risk assessment to share all necessary information with all relevant regulators and agencies) on active and potential risk flags to be able to reach out and support participants if their risk situation changes. This is critical given that many agencies have responsibilities for

safeguarding. The new National Disability Supports Quality and Safeguards Commission in particular can provide valuable regulatory intelligence to flag issues raised by a participant that may need additional safeguards (for example, if they made a complaint about a provider).

The process is depicted in Figure 160 below. It is important to note that while we have identified factors to consider in the development of this risk assessment and safeguard building process, the process should be fully developed through extensive work with people with disability, their families, carers, supporters and technical experts to ensure its effectiveness.

Figure 160: Risk assessment and safeguard building process

Prior to the needs assessment

Participants have a conversation with a trusted person about the risks in their lives.

Resources will be available online to support participants to have these discussions and to help them to identify risks.

Participants use this discussion to self-report on risk prior to the needs assessment.

During the needs assessment

The participant, with their chosen supporters, leads a conversation about risk with the assessor.

The assessor asks questions using the information from the needs assessment form.

The conversation will discuss what risks the participant faces and what responses can be put in place.

Following the needs assessment

Outcomes of the full needs assessment (including risk assessment) are recorded in an accessible format.

Outcomes of the risk assessment inform the budget setting process.

Participants work with their Navigator to plan and implement safeguards in response.

Check-in on progress

Navigators identify and help participants to respond to risks as they emerge.

Participants may be referred to other agencies for safeguarding support (such as state and territory Community Visitor Schemes).

Government agencies identify and flag if the participant is facing increased risks through consent-driven data and information sharing.

The risk assessment can be updated over time, and through the formal change of circumstances process.

Expanded range of safeguards

The second idea we proposed and sought feedback on was to expand the range of safeguards available to participants on an individual basis, to be deployed based on this risk assessment and to operate alongside system-level regulatory safeguards.

We proposed a mix of 'general safeguards' available to all participants as needed that focus on building capacity, natural safeguards and community connections; and more intensive 'targeted safeguards' that could be applied where participants face higher levels of risk. These would not necessarily all be funded or provided by the NDIS, but the NDIS could play a key role in connecting participants to them as needed, particularly where these respond to risks outside the NDIS.

Some of these supports would be accessible through the individual budget setting and risk assessment process as needed (for example, funding to build networks of support, and for independent support for decision-making). Other supports would be accessible through foundational supports (for example, Navigators, information and advice, and individual capacity building supports such as peer support, independent individual advocacy and self-advocacy). We also identified the importance of timely responses to consider the need for any additional supports if a participant's circumstances change in a way that could impact their safety (such as the incapacitation of a primary carer).

This proposal received broad support from submissions, with particular support for increasing access to capacity building and similar supports. Some submissions focused on the need to increase the supply of these safeguarding supports. Others identified additional priorities, such as training to ensure providers support participant choice, and focusing on supports that help participants to develop socially valued roles. One submission identified a need for information resources targeted towards people facing intersectional discrimination and inequality (such as First Nations and culturally and linguistically diverse communities) to provide effective support to them when managing risks.[2191] Some submissions emphasised the need for protections to be developed to mitigate any potential risks posed by natural safeguards, and the need to support carers to be effective natural safeguards.

> *"...educate and support carers to set up those informal safeguards for their family member. Get the word out there about the legal and advocacy services that can help with these things. If I know where to go and how to access these things, I can teach my child how to do it too" – Carer[2192]*

We note that this risk assessment and safeguard building process is focused on participants. However, many of the safeguards described, such as information resources for thinking about and discussing risk and other capacity-building supports (such as peer support and self-advocacy) will be more widely available for all people with disability through general foundational supports. This reflects the importance of widely available safeguards and supports to helping all people with disability, not just participants, manage risk in all aspects of their lives.

2.2.4.   Action & Implementation Details

📑 Action 16.2: The <u>National Disability Insurance Agency</u> should design, pilot and implement a new individual risk assessment and safeguard building process

This process should be participant-led and focus on their strengths and ways in which their capacity can be built. It should be integrated into needs assessment processes to more consistently determine a level of need for each participant (see Action 3.4). This process should connect participants (with the help of Navigators) to a range of individualised safeguards (see Action 16.3) including support for decision-making (see Action 5.3), funded through both foundational supports and individual reasonable and necessary budgets. This process could also address the potential need for a Behaviour Support Plan (see Action 18.2). The process should be designed with participants and families through the NDIS Experience Design Office (see Action 24.3) as part of reforms to the broader participant pathway (see Recommendation 3).

Implementation detail:

- The NDIS Experience Design Office (see Action 24.3) should be responsible for the design and testing of a new individual risk assessment and safeguard building process, prior to implementation by the NDIA. The development of this process should be linked to the development of assessment processes to more consistently determine a level of need for each participant (see Action 3.4), and should be developed working closely with people with disability, their families, carers, supporters and technical experts, the Department of Social Services (DSS), the NDIA and new National Disability Supports Quality and Safeguards Commission. The individual risk assessment and safeguard building process should include the following key stages:

  - Prior to the needs assessment, participants could have an initial conversation about risk and safety with a trusted person (for example, a friend, family member or health professional), supported by self-assessment resources made available online. They would use this conversation to help complete the risk assessment sections of the general needs assessment form.

  - During the needs assessment, the assessor and participant (as well as any chosen supporters) should work together to understand what risks might be present in the participant's life and what safeguards could be put in place in response. This discussion would be informed by the information provided in the needs assessment form, and include relevant assessments of need for particular supports (such as the need for decision-making supports – see Action 5.3). This process could also provide an opportunity to identify the potential need for a Behaviour Support Plan (see Action 18.2).

- The risk assessment should be recorded in an accessible format that can be used and reviewed with other needs assessment documentation, including to inform the development of the reasonable and necessary budget. Participants should be able to access and share assessment outcomes with their Navigator, supporters, families and providers to help them discuss and manage risk together.

- Following the assessment, the Navigator should be responsible for working with the participant and their supporters to plan and implement safeguards in response. This should include considering and implementing a range of individualised safeguards (see Action 16.3), including both supports funded through foundational supports and, where appropriate, individual reasonable and necessary budgets.

- There should be ongoing monitoring and review strategies to identify and respond to changes in a participant's life that may impact their safety. Navigators should play a central role in identifying and responding to risk. NDIS and other safeguarding agencies (for example, Community Visitor Schemes and adult safeguarding agencies) may also engage with participants, identify and flag situations where the participant is facing increased risk, and share this information with relevant agencies. This should include identifying and responding where a revised risk assessment is needed.

- The NDIS Experience Design Office and other relevant agencies should have regard to the following considerations in designing, testing and implementing the individual risk assessment and safeguard building process:

- Ensure the risk assessment process is participant-led and focused on transparent, meaningful and trusted conversations with participants and their chosen supporters about risk, safeguarding and quality supports, centring the participants' point of view. Participants should have access to appropriate support to assist with the discussion, such as support from family or an independent supporter (see also Recommendation 5). A key focus must be the psychological safety and wellbeing of the participant.

- Take a capitals-based approach (considering a person's personal, knowledge, material and social resources) that assesses risk and identifies and implements safeguards (such as those recommended in Action 16.3) that support the participant to respond to their individual circumstances and environmental and social factors.

- Include funding, where appropriate, in individual reasonable and necessary budgets to allow participants to access specific safeguards.

- Support assessors, Navigators, families and other supporters with training materials and information resources to help them engage in these conversations with participants in a way that is trauma-informed, uses a culturally responsive service model and understands First Nations concepts of disability.

- Develop publicly available information resources, including self-assessment resources and information on having effective conversations about risk and identifying risk

factors, to support participants and their supporters in considering risk and having these conversations.

- Incorporate monitoring and review strategies, including seamless information sharing between government agencies about key risk factors and flags (in line with improved information sharing arrangements (see Action 19.2) and with appropriate participant consent sought during the initial risk assessment). Particular risk flags could include settings where participants have limited natural safeguards or where they are at higher risk of coercion by providers. DSS, the NDIA and new National Disability Supports Quality and Safeguards Commission should collaborate on the development of further potential risk flags, as well as mechanisms for sharing and responding to such flags.

- Build on existing work, including the NDIA and NDIS Commission's joint approach to supporting at-risk participants, the NDIA's Participant Safeguarding Policy, and work on risk factors underway as part of the Safety Targeted Action Plan under Australia's Disability Strategy 2021-2031.

- Provide access to safeguarding supports, public information and resources for people with disability who are not participants through foundational supports to help them identify and manage risks in their lives, noting that they will not have access to this more tailored risk assessment and safeguard building process.

Action 16.3: The <u>Department of Social Services</u>, working with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and other agencies where relevant, should ensure participants can consider and access a wider range of safeguarding supports

Safeguards offered should include a range of developmental, preventative and corrective safeguards. Safeguards should prioritise capacity building, natural safeguards and community connections where possible, with more intensive support for participants facing higher risks. Safeguards should be funded through both foundational supports and individual reasonable and necessary budgets, depending on the level of need for different safeguards and optimal arrangements for ensuring access.

Implementation detail:

- The Department of Social Services (DSS), the National Disability Insurance Agency and new National Disability Supports Quality and Safeguards Commission (working with other agencies) should make improved general safeguards widely available to participants, with a focus on building capacity, natural safeguards and community connections. These

safeguards should be delivered generally as widely available resources or as foundational supports (see Recommendation 1.2), and should include:

- Accessible information supports about risk, safeguarding and quality supports – for example, a refreshed Participant Information Pack focused on building capacity to manage risk, and other media resources such as scenario-based videos or theatre to explore risk and safeguarding concepts. This should include dedicated education and information resources for First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities, developed by (or in collaboration with) their community and/or peak representative bodies.

- Connections and access to programs that build community connections and inclusion – such as organisations that help build connections (for example, circles of support, community circles, Microboards and peer networks), and support to be involved in mainstream rather than disability-specific social and community activities. These activities should focus on building a participant's natural safeguards and support them to have valued roles in their communities. In some cases, participants would be supported by Navigators to use their individual budgets to fund these connection-building programs.

- Connections and access to a range of supports for participants to make their own decisions (see Recommendation 5).

- DSS, the NDIA and new National Disability Supports Quality and Safeguards Commission (working with other agencies) should make available a range of targeted safeguards as more intensive supports for participants experiencing heightened levels of risk. These safeguards should include:

- Tailored education programs and information resources – for example, funding for training for participants and their supporters to understand rights, risk and safety, or funding for information resources about safety that are tailored to the circumstances or communication needs of the individual participant.

- Warm referrals across systems to connect participants to the right sources of support to manage safety issues.

- Pathways to ensure improved access to individual advocacy services when participants need it most as part of a strengthened approach to disability advocacy (see Action 1.5).

- Priority reassessment triaging for participants experiencing higher risks to respond to changes that may result in need for additional funding for safety-critical supports (see Recommendation 3).

- Referrals into Community Visitor Schemes for outreach (see Action 16.4).

2.3. State and territory-delivered safeguarding mechanisms are inconsistent and their role and status in the NDIS is unclear

As described above, risks for people with disability do not just occur in the context of the NDIS. People can experience risk in a range of different systems and life contexts, such as long-term social or economic disadvantage. As a result, the NDIS cannot be solely responsible for responding to every risk that a person faces, but must be able to connect people to the help they need.

There are existing state and territory programs that can help participants experiencing higher risk to get the support they need, such as Community Visitor Schemes (CVS) and adult safeguarding agencies. However, these programs are not consistently available nationwide and have not been well integrated with the NDIS. There are opportunities to improve and expand these programs to be more effective in supporting participants, as well as other people with disability, to be safe.

2.3.1.   Community Visitor Schemes are vital safeguards that can be enhanced through greater consistency and integration into the NDIS

One of the primary mechanisms for proactive, outreach-based safeguarding are state and territory-operated CVS. CVS visit and engage with people in higher risk locations or circumstances (for example, in supported accommodation and under guardianship arrangements) to support them with upholding their rights, making decisions and identifying risks or problems.

Many reports have canvassed the importance of CVS to the safety of the people they visit.[2193] The 2016 NDIS Quality and Safeguarding Framework specifically identified these programs as a key safeguard for people with disability facing significant risks to their safety, health and wellbeing.[2194] We agree, noting that CVS play a vital role in identifying problems on the ground without the need to receive a complaint or enforce a regulation. In addition, they are a vital source of information for regulators and other agencies to respond if there are problems with a service. Above all, however, their greatest strength is their ability to support the wellbeing of the people they are visiting:[2195]

> *"Mark has two regular activities – barista training and cooking classes weekly – but would like to consider other options. He told the [CVS] he would like to participate in a local Men's Shed… The [CVS] spoke with the manager of the accommodation service… The manager and Mark's team will also follow up local Men's Sheds and opportunities for a holiday" – NSW Official Community Visitor Annual Report* [2196]

However, there are several issues that require reform for CVS to be a truly effective safeguard for participants, among others.

1. There has been ongoing debate around which level of government should operate CVS, and what service systems they should cover. This has resulted in inconsistent arrangements across the country, with only six states and territories operating CVS that visit people with disability and not all of them visiting NDIS services, creating confusion for people with disability.[2197] Tasmania and Western Australia operate similar programs but have not developed disability-specific visiting services.[2198]

2. CVS have traditionally visited specific 'higher risk' sites, such as government commissioned disability homes and care services. However, the legislative and operational arrangements underpinning some CVS have not been updated to reflect the way disability services are now delivered in a range of public and private settings, meaning some participants no longer have access to a visitation program because their services are delivered at home or in community settings.[2199]

3. The cultural appropriateness of existing CVS programs has also been raised, with calls for the development of a culturally responsive model to meet the needs of First Nations people with disability.[2200]

4. With the NDIS Commission established as the regulator of NDIS-funded service providers, it is sometimes unclear what distinct role CVS play in this system.[2201]

5. There have been reports of difficulties for CVS in collaborating with the NDIS Commission and identifying all of the participants they should be visiting, because of incomplete information sharing by the NDIS Commission and the NDIA. This has meant they are unable to effectively identify and respond to issues as they arise.[2202]

In response, we identified and sought feedback on several changes in our May 2023 'Participant Safeguarding Proposals Paper'.[2203] Several main issues where raised in the submissions we received – who should operate CVS, what the primary role of CVS should be, who and where CVS should visit, and whether and how CVS should be able to deliver outreach in private homes.

On the question of who should operate CVS, there was strong support for using the existing federated structure as a platform, while also seeking more nationally consistent approaches and the ability for participants anywhere in Australia to have access to similar levels of outreach. We also heard this expanded coverage should be developed in a way that ensures it is safe and culturally appropriate for different communities.

On the role of CVS, several submissions highlighted the important role CVS could play in referrals to relevant NDIS agencies and emphasised the need to maintain their ability to regularly visit service providers without needing permission. While there was general agreement on the wellbeing-focused role of CVS, some submissions highlighted the importance of CVS maintaining their role as a key source of information for regulators.

We agree on the importance of this role and emphasise the need for effective information sharing arrangements to be operationalised between CVS and relevant regulators, including the new National Disability Supports Quality and Safeguards Commission. For example, information provided by CVS could inform regulatory compliance activities, as well as areas for focus in the auditing of providers.

> *"... the work of Visitors should be recognised as an important complement to the work of [regulators] – Visitors hold valuable information that can help to inform the prioritisation of monitoring and compliance activities, and the management of risks to participants." – NSW Ageing and Disability Commission*[2204]

On the question of who and where CVS should visit, several submissions emphasised the need for all CVS to cover disability accommodation settings, regardless of funding status (for example, Supported Residential Services that are privately operated accommodation services and have not traditionally been covered by CVS).[2205] Others raised concerns about our proposal for CVS to cover all NDIS services, describing it as disproportionate to risk given the breadth of services available through the NDIS.[2206]

In response to this, we note that it is not anticipated that CVS would have capacity to visit all sites. CVS would need to develop prioritisation strategies that take account of participant risk assessments, ensuring that those who are at highest risk have access to a visitation service. A key input to inform this prioritisation should be referrals to the relevant CVS of participants facing higher risks and with more limited natural safeguards from the risk assessment process described in Action 16.2.

On the question of outreach and visits in private home settings, there was some support for the idea of visitors being able to reach people experiencing higher risk generally, not just in formal disability-specific settings. We were interested to observe strong support from some stakeholders for an opt out (rather than opt in) model for such visits.[2207] However, we received limited feedback from submissions on the issue of whether people should be able to opt in or opt out of this service.

Noting the significant privacy implications of these proposals, we suggest that comprehensive design with people with disability is required to develop an appropriate approach that manages these various considerations and perspectives.[2208]

While there is a case for CVS to be able to visit people at risk wherever they live or receive services, more work is needed to determine how this should be operationalised in a risk-proportionate way. As noted above, the risk assessment process described in Action 16.2 provides an opportunity to identify participants who would most benefit from outreach in private settings, explain these benefits to participants, seek appropriate informed consent, and refer them to the relevant CVS.

> *"Outreach and visitation might work well if people understand well what outreach and visitation include and therefore can opt in/out (and can change their option overtime)." – Participant[2209]*

From the feedback received through consultation, it is clear that CVS are a critical safeguard for people with disability across Australia. Nationally consistent approach to state and territory-operated outreach and visitation are needed so that all people with disability have access to this key safeguard. CVS in each state and territory must be developed and enhanced to deliver high quality outreach that is focused on the wellbeing of the people they visit, while working closely with the NDIA, the new National Disability Supports Quality and Safeguards Commission and other agencies to ensure effective interfaces with the NDIS and other safeguarding systems.

We are recommending a reform pathway that will help to make CVS more effective, inclusive, better connected with the NDIS safeguarding system, and more clearly focused on supporting the

wellbeing and rights of the people they visit. This is consistent with the direction taken by the Disability Royal Commission in its recommendations on CVS.[2210]

States and territories should deliver these enhanced programs with greater national consistency on key features and areas of shared interest, such as the ability to visit certain locations unannounced and to receive referrals from other agencies like the NDIA and NDIS Commission (including through the risk assessment process described in Action 16.2). Maintaining these schemes at the state and territory level will also allow them to continue using and building on existing approaches and strengths that are optimal for both their local needs and achieving a highly effective national network as quickly as possible, such as the use of paid visitors or volunteers.

Finally, we emphasise the important role CVS play as a cross-system safeguard. CVS do not just visit disability support providers or people with disability but visit a range of different services and people experiencing higher risk (for example, services for people experiencing homelessness, mental health services and detention centres).[2211] These important roles must continue and could be enhanced by some of the reforms we are proposing.

2.3.2.   Emerging adult safeguarding systems can play a key role (alongside child protection systems) in responding to the different risks participants face, if implemented consistently

Adult safeguarding agencies (ASAs) are a new and emerging service offering among state and territory governments.

The ASA concept emerged from the Australian Law Reform Commission (ALRC) 2017 report *Elder Abuse – A National Legal Response*, which recommended a suite of reforms to establish agencies to support all people aged 18 and over who: have care and support needs; are being abused or neglected, or are at risk of abuse and neglect; and are unable to protect themselves from abuse or neglect because of their care and support needs.[2212]

Similar concepts exist internationally, such as Adult Safeguarding Boards administered by local authorities in the United Kingdom; and are mirrored in the existing child protection function that is the responsibility of all states and territories.[2213]

Responses by the states and territories to the ALRC recommendations to date have been varied, with New South Wales and South Australia the furthest progressed towards implementing ASAs in line with the ALRC's recommendation.[2214] However, despite the ASAs in these jurisdictions having been in operation for several years, their roles, responsibilities and authority in the context of the NDIS remain unclear.

The models proposed for these programs, and now in operation in some states and territories, respond to the need for a wellbeing-focused approach to helping people experiencing higher risks (including participants and other people with disability) – presenting a number of benefits and opportunities. ASAs are intended to be multi-disciplinary and cross-government, allowing someone experiencing higher risk to get support regardless of where or how an issue has arisen – whether within a service system or within their family or domestic circumstances.[2215] Their proximity to other services delivered by states and territories also supports this.

"… you can actually see a lot of worrying things happen across mainstream universal services but you can't… they're not all registered with the NDIS. So where are we going to go to safeguard people? What are the safeguards that exist? I don't think there are enough of them" – Tasmanian disability advocate in DANA submission to the Disability Royal Commission[2216]

ASAs also provide a clear place for reports of abuse, neglect or other concerns to be made, enabling the people who are closest to a person experiencing higher risk to raise concerns and support them to get help if needed.[2217] Further, for people experiencing intersectional discrimination and inequality, particularly for First Nations people with disability, these agencies have the opportunity to provide culturally safe support, engaging effectively with First Nations peaks and people to respond to and address their concerns.[2218]

ASAs have the opportunity to be designed from their beginning to set the standard for other government agencies in providing culturally safe, accessible and community-led programs. Finally, the ASA approach allows for the coordination of state and territory responses to an active risk which, when combined with information sharing with relevant NDIS agencies, would make the system easier to navigate and streamline the experience of participants seeking help.[2219]

Combined with the use of state and territory CVS to identify and start responding to the risks and challenges people face, ASAs could become a vital participant-facing one-stop-shop to raise and seek support in response to NDIS and broader safeguarding issues, working in coordination with the NDIS Commission. ASAs could offer an important first port of call for people seeking help and a key source of holistic support for problems across different service systems. Participants could be referred to ASAs where the NDIA or NDIS Commission are unable to give them the support they need with a particular issue (for example, for issues arising outside the NDIS). Similarly, where issues arise that directly relate to the NDIS (for example, concerns about a provider breaching regulatory obligations), ASAs would be able to refer the issue to the NDIS Commission for further action.

For ASAs to deliver on this opportunity to contribute to NDIS safeguarding, there must be a true 'no wrong door' approach and effective referrals and information sharing between ASAs, other state and territory agencies, and Australian Government agencies. Similarly, to support ASAs to provide a one-stop-shop and first port of call, there should be a single national phone number for raising risks of harm to people with disability that directs to the relevant state or territory adult safeguarding or child protection agency, as part of a no wrong door approach.

2.3.3.   Action & Implementation Details

📄 **Action 16.4: State and territory governments, with support from the Department of Social Services, should ensure participants can access high-quality, nationally consistent Community Visitor Scheme offerings that interface with the NDIS**

State and territory-operated schemes should be focused on supporting the wellbeing of the people they visit, including developing capacity and supporting individuals to manage risks, raise issues and resolve problems. Community Visitor Schemes should also play an enhanced role in sharing insights with regulators to support regulatory activity. State and territory roles should be supported by the Department of Social Services through a new National Community of Practice, with leadership from the new National Disability Supports Quality and Safeguards Commission on relevant operational reforms, including improved information sharing protocols.

Implementation detail:

- State and territory governments (supported by the Department of Social Services (DSS) and the new National Disability Supports Quality and Safeguards Commission through a new National Community of Practice) should prioritise the following immediate reform needs within 1-2 years:

  - A National Community of Practice should be established to drive these reforms, coordinated by DSS and comprising the new National Disability Supports Quality and Safeguards Commission, all existing CVS and relevant state and territory policy departments. It should build on and expand the current state-led Community of Practice.

  - The National Community of Practice should improve collaboration between all agencies and agree a shared direction for policy reforms, while building on the strengths of existing CVS. This should include developing national principles regarding the role of CVS and interfaces with the NDIS. National principles should aim to develop consistent approaches to areas of shared interest (for example, prioritisation strategies to identify those who will most benefit from outreach, and the ability for visitors to attend certain sites unannounced) while allowing jurisdictions to maintain features appropriate for their jurisdiction (for example, different service models such as the use of paid or volunteer visitors).

  - CVS should remain a state and territory responsibility and all Australian governments should affirm the important role of CVS in safeguarding people experiencing higher risks (including participants), and commit to the primary role of CVS being focused on supporting the wellbeing of people they visit and helping them to raise issues (rather than monitoring regulatory compliance). This should include providing appropriate resourcing and legislative powers, operationalising effective information sharing arrangements with regulators (to inform regulatory compliance activity), and considering any necessary changes to Australian Government or state and territory legislation to recognise and support the role of CVS.

  - Priority should be given to the development of a First Nations CVS Strategy in each jurisdiction. The Strategy should be designed with First Nations communities and outline culturally safe visiting approaches for First Nations people, initiatives to drive

recruitment of First Nations people as visitors, and how CVS should collaborate effectively with First Nations representative organisations and communities.

- State and territory governments (supported by DSS and the new National Disability Supports Quality and Safeguards Commission through the National Community of Practice) should implement the following medium-term reforms within 2-3 years:

  - CVS covering higher-risk NDIS services and participants in higher-risk circumstances should be established in every state and territory, with a focus on ensuring wellbeing, promoting rights and building capacity.

  - A program for visits to private homes and other private settings should be designed by the National Community of Practice with participants, disability representative organisations and service providers. This program should enable CVS to attend any site where outreach has been requested, provide support to participants, and make referrals to regulators where appropriate. This design process should also determine whether participants should be able to opt in or opt out of these visits.

  - Information sharing arrangements between CVS, state and territory regulators, the new National Disability Supports Quality and Safeguards Commission and the NDIA should be established and/or improved to enable the sharing of risk-related information in all directions. These changes should enable warm referrals to CVS from the risk assessment process and national phone service (see Actions 16.2 and 16.5), and referrals from CVS to Australian Government and state and territory regulators where potential regulatory breaches and provider compliance concerns are identified.

- State and territory governments (supported by DSS and the new National Disability Supports Quality and Safeguards Commission through the National Community of Practice) should implement the following longer-term reforms within 3-5 years:

  - CVS should prioritise outreach based on a person's level of individual risk (rather than solely focusing on visiting particular sites). This should be informed by factors affecting an individual's ability to manage risks, such as service type and available natural safeguards.

  - Best practice approaches should be identified and promoted to work towards national consistency, including by collaborating with researchers to identify these approaches. Best practice and national consistency should be promoted on issues such as training for visitors and reporting standards for improving the quality of information shared between agencies. It should also include developing best practice strategies for engagement with communities facing compounding risk of intersectional discrimination and inequality such as women, LGBTIQA+SB people and culturally and linguistically diverse communities (alongside the First Nations CVS Strategy identified above).

- A set of benchmarks and outcomes for measuring and evaluating CVS performance should be developed. This should include engaging with people being visited to gain their feedback where possible. These outcomes and benchmarks should be publicly reported on and used to hold governments to account for effective delivery.

- CVS should be integrated with, or closely linked to, adult safeguarding agencies (see Action 16.5).

🗐 Action 16.5: State and territory governments should establish or improve adult safeguarding agencies to deliver a universal service offering for the safeguarding of all people at risk of harm, including people with disability

Adult safeguarding agencies (as recommended by the Australian Law Reform Commission and complementary to established child protection agencies) should provide holistic, person-centred safeguarding for anyone who needs them and a one-stop-shop to raise concerns about risks of harm. These agencies should work closely with and complement disability support ecosystem safeguarding bodies through information sharing and collaboration. These agencies should address the need for support across different service systems and with a variety of different risks, within and outside the NDIS. This should include establishing a single national phone number for raising concerns regarding the safety of a person with disability at risk of harm and taking a 'no wrong door' approach on safeguarding issues.

Implementation detail:

- State and territory governments should urgently progress adult safeguarding reforms to support participants and other people with disability at heightened risk of harm. This should involve establishing, empowering and promoting adult safeguarding agencies to deliver holistic safeguarding support to any adult with care and support needs at risk of harm (as outlined in Recommendations 14-1 to 14-8 of the Australian Law Reform Commission 2017 report *Elder Abuse - A National Legal Response*). These agencies should work closely with and complement NDIS agencies to support people with disability at heightened risk of harm with the necessary support they need, independent of any funding programs through which they may receive supports.

  - These agencies should establish strategies to ensure appropriate support for communities affected by compounding risks of intersectional discrimination and inequality, such as First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities. This should include involvement of these communities in the development and operation of these agencies.

  - For children and young adults, established child protection agencies should maintain primary responsibility, collaborating with adult safeguarding agencies and NDIS

agencies as the child grows up to ensure support is maintained as they transition to adulthood.

- State and territory governments (supported by the Australian Government) should establish a single national phone number (with place-based diverting to state and territory adult safeguarding and child protection agencies) that can be used to raise concerns regarding the safety of a person with disability at risk of harm. This should provide a one-stop-shop, with effective triaging and referrals to relevant authorities and agencies. This should also link closely with the NDIA and new National Disability Supports Quality and Safeguards Commission to make and receive referrals as needed to support people with disability with different safeguarding concerns.
- State and territory adult safeguarding agencies and child protection agencies and Australian Government NDIS agencies should take a true 'no wrong door' approach on safeguarding issues, including effective referrals and two-way information sharing. This should enable adult safeguarding agencies and child protection agencies to provide direct, intensive safeguarding support to at-risk participants, and for Australian Government agencies to be made aware of issues relating to the quality and safety of Australian Government funded disability supports.

3. A new risk-proportionate model for regulation of providers and workers

- Current regulation and registration of NDIS providers is not sufficiently proportionate to the varied risk profiles of different supports and providers, creating both gaps in regulatory oversight particularly for higher-risk support delivery, as well as excessive burden and duplication for lower-risk support delivery. Current regulation and registration arrangements also result in inequitable treatment between providers delivering similar supports, and the ability for most of the market to opt out of most regulatory requirements. The ability for providers to opt out of most regulatory requirements inappropriately places too much burden on participants to manage risk themselves, and prevents the NDIS Quality and Safeguards Commission (NDIS Commission) from having the visibility of the market necessary to apply a proactive and risk-based approach to prevent harm and promote quality improvement.
- Workers are critical to the experience of participants and to safety and quality in the delivery of supports. However, there are limited preventative safeguards that apply to all workers in the NDIS, with limited coverage of the NDIS Worker Screening Check and concerns about the adequacy of worker training and competencies. The current operationalisation of NDIS worker screening also requires improvement and must be better streamlined and harmonised with other worker screening arrangements, to remove barriers and delays for workers and providers, and ensure that all vulnerable people (adults and children) receive the protections they need to be safe.

- Regulatory settings have not been proactively updated to address long-standing quality and safeguards issues or respond to changes in NDIS markets. This exacerbates gaps in regulatory oversight, creates uncertainty for participants, providers and workers about what is expected, and acts as a barrier to innovation.
- Reform is required to deliver a new graduated and risk-proportionate regulatory model for the regulation of providers, with mandatory registration or enrolment of all providers and requirements that are proportionate to the risks of a provider's activities and operations. This should be supported by the application of preventative safeguarding requirements to more workers. This will strike a better balance between preventing harm, supporting choice and control, encouraging innovation and enabling the whole market to thrive.
- This new graduated and risk-proportionate regulatory model should be supported by a proactive approach to respond to both long-standing issues and emerging changes and innovations in the market. This should address quality and safeguards issues as they emerge, while enabling innovation in the interests of participants.

Recommendation 17: Develop and deliver a risk-proportionate model for the visibility and regulation of all providers and workers, and strengthen the regulatory response to long-standing and emerging quality and safeguards issues

⬚ Legislative change required

- ⬚ Action 17.1: The <u>Department of Social Services</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should design and implement a graduated risk-proportionate regulatory model for the whole provider market.
- ⬚ Action 17.2: The <u>Department of Social Services</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should develop a staged implementation approach to transition to the new graduated risk-proportionate regulatory model.
- ⬚ Action 17.3: The <u>Australian Government</u> should amend the *National Disability Insurance Scheme Act 2013* to remove the link between a participant's financial management of their plan and the regulatory status of their support providers.
- ⬚ Action 17.4: The <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should expand the coverage of worker screening requirements.
- ⬚ Action 17.5: The <u>Department of Finance</u> and the <u>Department of Social Services</u>, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should improve, streamline and harmonise worker screening processes for care and support workers.
- Action 17.6: The new <u>National Disability Supports Quality and Safeguards Commission</u> should be resourced to strengthen compliance activities and communications to respond to emerging and longstanding quality and safeguards issues, and market developments and innovation.

3.1. Provider regulation is not sufficiently proportionate to the risks of support delivery, creating both gaps in oversight and excessive regulatory burdens, and undermining the value and acceptance of registration

Current regulation and registration of NDIS providers has created both gaps in the regulatory oversight of providers, particularly for providers delivering high-risk supports, as well as excessive burden and duplication for providers delivering lower-risk supports. Gaps in regulation occur because most of the market can opt out of most regulatory requirements. Burden and duplication occurs where regulatory requirements are not commensurate with the level of risk posed by a provider's support delivery or are similar to other requirements that a provider has met in other regulatory systems.

A new graduated and risk-proportionate regulatory model for the registration or enrolment of all providers is required to better align regulatory requirements to the risk of support delivery, while applying proportionality to address burden and duplication where appropriate. This model must also incorporate new supports and functions proposed in other recommendations made by this Review, to ensure consistent regulation and safeguarding. A more risk-proportionate approach to the regulation of providers will strike a better balance between preventing harm, supporting participant choice and control, encouraging innovation and enabling the market to thrive.

3.1.1. Registration is a key preventative safeguard designed to ensure safe and high-quality providers deliver fit-for-purpose supports to participants

The *National Disability Insurance Scheme Act 2013* (NDIS Act) and the 2016 NDIS Quality and Safeguarding Framework established tools and strategies for the NDIS Commission to implement a range of preventative safeguards to regulate providers and workers, and ensure a safe, high quality provider market delivering supports to people with disability.[2220] These preventative safeguards were intended to work alongside developmental and corrective safeguards (see Box 88) to ensure safe, high-quality supports.

Key preventative safeguards delivered by the NDIS Commission in respect of providers and workers include the NDIS Code of Conduct applied to all providers and workers; registration, NDIS Practice Standards and auditing applied to some providers (discussed in this section); and the NDIS Worker Screening Check applied to some workers (discussed in Section 3.2).

Currently all NDIS providers and workers are subject to an enforceable NDIS Code of Conduct, which is a preventative safeguard that describes behaviours for providers and workers involved in support delivery.[2221] The NDIS Code of Conduct expresses generally held ethical expectations that any reasonable organisation or individual should act on in supporting people with disability. The development of the NDIS Code of Conduct took into consideration broader policy, legislative and regulatory environments to develop these broad expectations, including work health and safety law, consumer law, and the United Nations Convention on the Rights of Persons with Disabilities.[2222]

The NDIS Code of Conduct provides a mechanism for the NDIS Commission to take action in response to unacceptable behaviour that falls short of community expectations using the range of corrective regulatory levers at its disposal. However, the NDIS Code of Conduct only describes high-level ethical expectations. It does not describe minimum acceptable standards for safe and appropriate service delivery, does not require any specific knowledge or expertise in support delivery, and does not describe the standards and behaviours necessary for a quality service.

To address these limitations, the *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018* (NDIS Provider Registration and Practice Standards Rules 2018) prescribe a registration process, including NDIS Practice Standards and Quality Indicators, which together create a benchmark for provider quality and indicators that demonstrate achievement of this benchmark.[2223]

Registration is a preventative safeguard that was designed to ensure that people working in the NDIS are reputable, well-managed, understand the needs of people with disability in support delivery, have the correct competencies to deliver supports, and have good practices.[2224] While registration is not a guarantee of either safety or quality, it does indicate a provider has taken steps to deliver supports professionally and competently, and that this has been independently assessed. It is also an important way of holding providers to account.

NDIS providers undertaking this registration process are subject to an audit (of varying intensity) by a third-party auditor against relevant NDIS Practice Standards and Quality Indicators. The results of this audit then inform the NDIS Commission's decision on whether to register the provider – alongside a suitability assessment of the provider and key personnel, which considers any findings or judgements in relation to fraud, civil or criminal proceedings, and any others matters the NDIS Commissioner considers relevant.[2225] Registered providers have additional obligations, including complying with relevant NDIS Practice Standards, reporting certain incidents to the NDIS Commission, having an appropriate complaints and incident management system, and ensuring that all workers in risk-assessed roles have an NDIS Worker Screening Check (see Section 3.2).

Registration is currently only mandatory for a limited number of high-risk support types – the development of behaviour support plans and implementation of restrictive practices, the provision of specialist disability accommodation, the provision of plan management services, and the delivery of all supports to Agency-managed participants. Registration is optional for providers delivering all other types of supports to self-managing and plan-managing participants.

3.1.2. How NDIS supports are delivered can present risks to participants, however many supports are currently delivered by unregistered providers with little regulatory oversight

The broad range of supports delivered in the NDIS – as well as the different types of providers they are delivered by – can present different types and levels of risk to participants. The use of providers subject to registration and regulatory oversight is one means of managing this risk, as these providers are required to demonstrate how they provide quality and safe supports.

It was initially envisioned that most participants would be Agency-managed, and therefore that most providers would be registered. Estimates made during the establishment of the NDIS Commission in 2016-17 assumed the proportion of participants self-managing would stabilise at 6 per cent (with no estimate provided for plan-managed participants).[2226] However, the proportion of participants who self-manage or plan-manage has grown significantly. As of June 2023, 29 per cent of participants self-manage all or part of their plan, and 60 per cent use a plan manager.[2227]

This high number of self-managing and plan-managing participants has driven the growth of an unregistered provider market that is much larger than originally expected. Similarly, the ability to access unregistered providers has driven demand for self-management and plan-management. Overall, this has resulted in a situation where unregistered providers deliver a wide range of types of supports, have access to a large proportion of the NDIS market, and can mostly opt out of regulation, including when delivering high-risk supports.

In April to June of 2022-23, over 154,000 unregistered providers received a payment from a plan-manager.[2228] Limited visibility of payments made by self-managing participants to unregistered providers (including who payments are made to and for what purpose) means the total number of unregistered providers is unknown and likely to be higher. This compares to a total of around 16,000 registered providers currently in the market.[2229] Box 90 provides insights on the number of registered and unregistered providers delivering supports in the NDIS, the types of supports they deliver, and the volume of payments made to these providers.

Box 90: Providers and payments by registration group (April to June, 2023) [2230]

The following data and insights relate to payments made to registered and unregistered providers in respect of Agency-managed and plan-managed participants. It does not include payments made by self-managed participants or the number of unregistered providers accessed by these participants.

Around **$8 billion was paid to registered and unregistered providers in April to June of 2023** for Agency-managed and plan-managed participants.

- **74 per cent ($5.9 billion) of total payments went to 14,130 registered providers and around 26 per cent ($2.1 billion) went to 154,409 unregistered providers**. While the market of unregistered providers is large, they are receiving a smaller proportion of total payments. This suggests unregistered providers are mostly being used for lower-cost supports and/or less frequently and/or are sole traders or very small businesses.
- **$4.9 billion (62 per cent of total payments) was paid in respect of plan-managed participants**, who are able to access registered and unregistered providers – **with 58 per cent ($2.8 billion) going to registered providers and 42 per cent ($2.1 billion) going to unregistered providers**. The remaining payments were made in respect of Agency-managed participants, who can only access registered providers.

The top five registration groups with the highest total payments were Daily Tasks and Shared Living ($2,380 million), **Assistance with Daily Personal Activities** ($1,521 million), **Community Participation** ($1,428 million), **Therapeutic Supports** ($634 million), and **High Intensity Personal Activities (** $325 million).

- Across each of these registration groups, more than half of total payments went to registered providers. Taken together, these registration groups accounted for 79 per cent of all payments made in the quarter.

Unregistered providers accounted for more than half of total payments made in the registration groups of **Communication and Information Equipment** (51 per cent), **Development of Daily Living and Life Skills** (60 per cent), **Household Tasks** (60 per cent), **Innovative Community Participation** (56 per cent), and **Interpreting and Translation** (62 per cent).

- Across each of these registration groups, unregistered providers delivered more supports than registered providers. However, these registration groups accounted for less than 3 per cent of all payments made in the quarter.

Some supports represent a higher inherent risk to participants and can be delivered by unregistered providers. We have identified some higher-risk support types, with differences in the proportion of these supports delivered by unregistered providers.

- Daily Tasks and Shared Living (which includes SIL supports) had total payments of $2,380 million, with 93 per cent of payments going to 3,127 registered providers, while 7 per cent of payments went to 8,852 unregistered providers.
- Early Intervention Supports for Early Childhood had total payments of $156 million with 65 per cent of payments going to 2,513 registered providers and 35 per cent of payments going to 7,810 unregistered providers
- Assistance in coordinating or managing life stages, transitions and supports (which includes non-specialist support coordination) had total payments of $243 million with 81 per cent of payments going to 4,378 registered providers and 19 per cent of payments going to 8,784 unregistered providers.

We have identified a range of concerns arising from the presence of a large, unregistered provider market able to deliver a wide range of supports and be accessed by a large proportion of participants.

Some supports that are currently not required to be delivered by a registered provider pose inherently higher risks to participants

This arises from the nature of the support being delivered or the setting in which it is delivered in, such as supports delivered in accommodation settings (that is, supported independent living supports) and early childhood supports.[2231] This is consistent with the findings of the NDIS

Commission's Own Motion Inquiry into Aspects of Supported Accommodation and the Disability Royal Commission, which identified that people with disability in supported accommodation settings often have limited preventative safeguards available to them (including lacking access to a wide range of providers, advocacy or natural safeguards). This is also consistent with the Early Childhood Early Intervention Reset, which noted the risk that families may be inappropriately influenced by providers delivering non-evidence-informed supports that may impact the long-term outcomes of children in the NDIS, therefore increasing the risk of early childhood supports.[2232]

We also note that intermediary supports, such as support coordination, can present a higher risk to participants because of the close relationship these providers have with participants, including visibility of supports around the participant, use of participant funding and overall participant wellbeing – as evidenced in part one of the NDIS Commission's Own Motion Inquiry into Support Coordination and Plan Management and the Disability Royal Commission.[2233] These inquiries identified concerns that some of these intermediary providers were not delivering supports with enough expertise, care or skill (such as not having the appropriate competency, training or qualifications where appropriate), as well as issues of fraud, integrity, and coercion.

The lack of regulatory oversight of supports, including those that may pose high risks, was also raised with us in submissions and other engagement.

> *"SIL should be regulated to ensure that; they are not overcrowded, and that individual privacy is maintained. This could be assisted by scheduling, clear boundaries being set..." – Dr Piers Gooding et al. (University of Melbourne)[2234]*

The NDIS Commission has no real visibility of the significant unregistered provider market, and has limited tools to respond to issues

The lack of visibility of the market prevents the NDIS Commission from understanding what is happening and whether responses are required to prevent harm and promote quality improvement, until something has already gone wrong. The NDIS Commission is not able to effectively monitor the market and proactively intervene to prevent harm and promote quality improvement. Even if issues are detected, there are limited tools available to respond and take corrective action because the unregistered market is not required to meet any specific standards in the delivery of supports beyond the basic ethical expectations in the NDIS Code of Conduct. It also means that there is no mechanism to explain to providers and workers the implications of the NDIS Code of Conduct.[2235]

The Disability Royal Commission identified similar issues, and these concerns were also reinforced to us in submissions and other engagement.[2236]

> *"[Unregistered] providers do not have to show compliance with NDIS safety, quality and workforce regulations. The lack of transparent control on quality standards and supervision would cause harm to NDIS participants...the lack of registration means there would be operations with unregulated quality standards, unaccountable operators, and little visibility on who receives payments, opening the door to fraud and*

scams as well as risks of violence, abuse, neglect and exploitation." – CASS Care Limited[2237]

While we were given many examples of excellent and innovative practices by unregistered providers, the reality is that many unregistered providers are 'flying below the radar.'

The 'opt out' nature of registration undermines its value and acceptance in the market

Registered and unregistered providers can often deliver similar supports, regardless of the risk that these supports may pose to participants, which results in inequitable regulatory requirements for providers.

Registered providers feel more scrutinised and subject to greater obligations than unregistered providers, who they are competing with to deliver similar supports. This is compounded by providers not seeing the registration process (and in particular the auditing process) to be of value to them or as something that contributes to the quality of their support delivery (see Section 3.1.4 for a discussion of some concerns about auditing and Section 4.2.2 for a discussion on refocusing audits on quality improvement).

> *"As a support coordination business, we are not required to be a registered provider. Now that we are registered, there appears to be little benefit in registering." – Provider[2238]*

We also heard throughout this Review from many registered providers expressing that, if the current regulatory framework is maintained, they would either deregister their entire business or parts of their businesses to minimise their regulatory costs and be able to compete on an equal footing with unregistered providers.

> *"OTA has heard from members that some auditor fees are excessive, and this impacts business operations. Some OTA members have reported that they enjoy the level of flexibility offered by providing services as an unregistered provider, including that they do not have to "deal with" [the NDIS Commission]. However, OTA is aware of concerns from some registered providers that this creates inequity because they undergo stringent registration requirements and so are disadvantaged due to registration and compliance costs." – Occupational Therapy Australia[2239]*

Higher than envisioned number of self-managing participants has resulted in limited visibility of payments

This includes who payments are made to and for what purpose. This creates challenges for ensuring the integrity of the NDIS (see Chapter 4) as there is no visibility of payments made to this much larger than envisioned unregistered provider market delivering supports to self-managing participants.

To enable the regulator to effectively prevent harm and promote quality improvement, as well as take action if something goes wrong, all supports and providers should be subject to appropriate regulatory requirements and oversight, and providers should not be able to opt out of regulation.

Regulatory oversight should be proportionate, holding providers to standards and requirements that are commensurate to the risk involved in different types of support delivery.

Proportionate regulatory oversight and requirements for the entire market would allow the new National Disability Supports Quality and Safeguards Commission to proactively monitor the market and prevent harm. It would also enable the new National Disability Supports Quality and Safeguards Commission to more readily identify and address issues through a variety of corrective means, including taking appropriate compliance action against breaches of the NDIS Code of Conduct, NDIS Practice Standards and other provider obligations as relevant.

3.1.3. While some participants value access to unregistered providers, too much burden is placed on participants to manage risk themselves

In addition to the issues outlined above, we are also concerned that the presence of a large, unregistered provider market, which can be accessed by the vast majority of participants, places too much burden on participants to manage risk themselves. Some participants are able to manage these complex risks effectively, but others are not.

We have heard that many participants highly value access to the unregistered provider market, particularly because of a perception that these providers are able to be more flexible and innovative than registered providers.

> "...many families we know who self-manage, tend to have great support staff in ordinary people as they have real choice and control over whom they employ and this tends to lead to less staff turnover, more consistency in staff leads to really getting to know the person with disability and their needs/interests and this ultimately leads to more trust and safety." – Family Advocacy[2240]

This aligns with recent research, including interviews with 30 self-managing or plan-managing participants and/or plan nominees, which found "pull factors included perceptions of better, more person-centred service, flexibility, innovation, social inclusion, and improved cost effectiveness associated with using unregistered providers".[2241]However, we also know that participants have varying degrees of capacity to manage risks in their lives independently. Given the majority of adult participants in the NDIS have a cognitive disability, many would benefit from support for decision-making. In addition, around 50 per cent of participants are children or adolescents and may require additional support, especially as they move towards adulthood.[2242]

Current assessments that determine whether participants can self-manage or plan-manage their plans – and therefore whether they can access unregistered providers – are focused on considering the participant's capacity to manage the funding in their plan, and do not sufficiently consider varying capacity to manage complex risks in the delivery of supports. This means that the requirement for providers to register is mostly determined by the way a plan is financially managed, with providers only requiring to register when delivering supports to Agency-managed participants, rather than the risk that support delivery may pose (except in limited circumstances).

The result of these arrangements and circumstances is that some participants may not fully understand their rights or the risks they are engaging with, and may have limited capacity to advocate for themselves in navigating these risks. This leads to an unreasonable expectation for people with disability to manage all risks themselves, which is inconsistent with other similar human services systems (for example, aged care).

We note that the benefits of registration to many participants have not been well explained by the NDIS Commission. While registration is not a guarantee of either safety or quality, it does provide assurance to participants that the provider has taken steps to ensure they are well managed and delivering supports in a professional and competent way, and that this has been independently assessed. It also means that there are stronger mechanisms available to hold providers to account. This lack of communication about what provider registration offers to participants has contributed to an erosion of confidence in the value of registration.

While we acknowledge that participants value access to the unregistered provider market, the current approach of allowing providers to largely opt out of registration and regulation leaves many participants potentially exposed to high levels of risk without appropriate preventative safeguards – particularly participants who have complex needs or circumstances. This puts the onus of managing these risks on individual participants, which is an inappropriate burden for many.

A greater emphasis on the use of preventative measures applied to all providers and participants will make the system work better for everyone and prevent harm to those most at risk

3.1.4.   The audit process is a critical part of registration, but is not as effective as it should be

Providers undergo an audit as part of the process of registration, which involves an independent assessment of a provider against relevant components of the NDIS Practice Standards by an external third party auditor.[2243] Auditing is a critical part of the registration process because it ensures that providers are independently assessed against the requirements in the NDIS Practice Standards to ensure that providers are well-managed and delivering quality supports in line with requirements. Auditing also provides an opportunity to identify areas for improvement in the quality of support delivery.

However, we have heard and identified a range of concerns regarding the effectiveness and quality of the audit process. These concerns mean the audit process is not as effective as it should be in assessing and promoting quality support delivery. They also lead to some providers not seeing the auditing process to be of value to them, contributing to negative perceptions about the registration process as a whole.

A frequently raised concern is that auditing is too focused on assessing the compliance of a provider's policies, procedures and other paperwork requirements. This appears to detract focus and effort from observing and assessing the quality of supports a provider is delivering, considering the voices and experiences of people with disability, and identifying opportunities for providers to improve quality (see Section 4.2.2 for further discussion of these issues).

"An audit program will always be required, however…more of the 'on site' audit could be spent with customers and staff rather than the 'fly-by' that we've experienced in the past (15-minute visits)." – Provider[2244]

"Overall, the sector is supportive of an agreed set of quality standards to guide and assess practice. However, providers have raised concerns about the cost and questioned the value of the audit process in driving continuous quality improvement." – National Disability Services[2245]

Concerns are also commonly raised about the time and cost burden associated with audits. The costs of audits can vary significantly, with some providers facing high costs. Audits can also be time-consuming, and providers sometimes face difficulties in finding available auditors. This means that finding an auditor, the time spent completing an audit, and the cost of this audit can be a source of frustration for providers, and can pose a barrier for some providers registering with the NDIS Commission. These challenges are compounded by a lack of proportionality, with audits not well targeted to the nature of a provider's support delivery or their compliance history. This means audits can be excessively burdensome for some providers.

"These costs are significant, managing service agreements, portal booking, staff training and audits. Auditing and registration costs in excess of $30,000 per annum not including full time Quality and Compliance team member at a cost of [approximately] $90,000." – Health Services Union (National) [2246]

"Although the approved quality auditor market has increased, and most identify they provide services across Australia, there remains limited Tasmanian based auditors. This results in an additional financial impost associated with travel related expenses for Tasmanian based providers." – Tasmanian Government submission to the Joint Standing Committee on the NDIS inquiry into the NDIS Commission[2247]

Concerns have also been raised about the capacity and oversight of auditors. Auditors are accredited by the Joint Accreditation System of Australia and New Zealand (JAS-ANZ), which assesses matters such as whether an organisation is competent and impartial to deliver effective audits generally.[2248] Auditors can then apply to be approved quality auditors in the NDIS, with the NDIS Commission responsible for approving auditors based on whether they will be able to properly conduct audits of support quality in accordance with the *National Disability Insurance Scheme (Approved Quality Auditors Scheme) Guidelines 2018.*[2249]

However, concerns have been raised – including through the Joint Standing Committee on the NDIS inquiry into the NDIS Commission – that auditors do not always have the necessary experience or capacity to effectively assess disability support quality, which can result in varied auditing experiences for providers.[2250] Similarly, we have heard concerns that audit teams do not necessarily include experts in support delivery or people with lived experience of disability, and that the lack of involvement of NDIS Commission staff in audits means they are not well-connected to the compliance history of a provider (see also Section 4.2.2).[2251] A particularly problematic

consequence of this is that poor audit quality in some instances, and the consequent failure to identify quality issues in these instances, then undermines the standing of all audited and regulated services.

We note the NDIS Commission is already taking steps to address some of these issues, as outlined in the Australian Government's response to the Joint Standing Committee on the NDIS inquiry into the NDIS Commission.[2252] This includes providing guidance for auditors on the collection of evidence from participants, designing models to include people with disability as consumer technical experts in the audit process, and regularly reviewing the cost of auditing. [2253]

However, more needs to be done. This chapter and our recommendations identify several key areas for improvement – firstly, incorporating greater proportionality and more flexibility into the use of auditing as part of a new graduated and risk-proportionate model for the regulation of providers (see Sections 3.1.5, 3.1.8 and Action 17.1); and secondly, refocusing auditing on the quality of support delivery and elevating the voices of people with disability to contribute to continuous quality improvement by providers, including ensuring auditors are capable of assessing support quality (see Section 4.2.2 and Action 12.2).

3.1.5. There is limited proportionality applied in the regulation of different supports, with providers sometimes subject to excessive burdens and poorly targeted regulation

Registration in the NDIS was designed to be proportionate to the risk and complexity of different types of support delivery.[2254] This includes proportionality in the NDIS Practice Standards that a provider is required to meet and differentiation in the intensity of auditing to demonstrate compliance with these standards. Providers delivering lower-risk and lower complexity supports and services undergo a lighter-touch 'verification audit', which involves a desktop audit of things such as expertise and qualifications, incident and complaints management policies, and risk management policies.[2255] Providers delivering more complex or higher-risk supports and services undergo a more intensive 'certification audit', which includes document reviews, site visits and interviews with workers and participants.[2256]

Within these different audit approaches (that is, verification or certification), the intensity of processes is intended to vary depending on other factors, such as the size of a provider and complexity of support delivery. The NDIS Commission states in current guidance that:

> "...*a provider providing support to a small number of participants is not expected to present the same level of evidence and documentation as a larger provider with many NDIS participants.*" – *NDIS Commission's Residential Aged Care Toolkit[2257]*

For example, individuals and partnerships registering for early intervention early childhood supports undergo a 'modified' certification audit against fewer NDIS Practice Standards than a larger organisation.[2258]

However, we have identified through submissions and inquiries that there is insufficient application of proportionality in registration, with the scope, coverage and intensity of standards and audits not necessarily proportionate to a provider's size or the risk and complexity of support delivery.

"OTA is of the view that the Framework could take a further nuanced approach to registration and auditing, that is based on a risk profile of certain support services, and size of business, and the existing regulatory frameworks that exist." – Occupational Therapy Australia[2259]

"The registration process (including the quality audit process) should be proportionate and measured, with higher levels of scrutiny and rigour applied to large providers or providers delivering complex or higher risk supports and services." – Disability Royal Commission Final Report[2260]

This means that some providers may be subject to audits where it may not be necessary, or subject to audits with a broader than necessary scope. This may include instances where providers have met similar standards elsewhere but are required to be audited against equivalent NDIS Practice Standards, or where providers are required to be audited against the full breadth of the NDIS Practice Standards when aspects may not be relevant to the provider's activities (for example, small businesses or sole traders being required to provide extensive evidence about their governance and operational management, which may be more appropriate for larger and more complex providers).

Concerns particularly arise in relation to registration renewal audits, where providers may be required to undergo a full in-depth audit even if issues of quality and safety have not previously been identified, or where information was accepted in a previous audit and has not changed but must be reassessed in an audit (for example, an acceptable policy about how a provider handles complaints and incidents).

"[We] recently underwent a mid-term audit even though the previous re-registration audit showed no corrective actions were required. Why did we need to be audited again in between audits?...The audit and registration process does not seem to include assessment of the relative risks for different service delivery types...." – SDN Children's Services[2261]

"As a small, independent business offering Support Coordination only, we are unfairly burdened by being treated the same as a large organisation/business offering multiple supports." – Provider[2262]

A more proportionate and flexible approach to the application of NDIS Practice Standards and auditing, that varies in scope and intensity based on the risk and complexity of support delivery, is critical to addressing issues of burden, duplication and cost. This should include identifying where the scope of audits could be more targeted, and where external auditing may not be necessary or can be supplemented, complemented or replaced with other regulatory tools to assess compliance – for example, providers self-assessing and attesting to compliance with standards and/or ongoing monitoring by the new National Disability Supports Quality and Safeguards Commission through a new provider outreach function (see Action 12.1).

3.1.6. Regulation can be duplicative and burdensome for some supports, undermining its acceptance and imposing unnecessary costs on providers

As noted above, registration in the NDIS requires providers to demonstrate evidence of meeting NDIS Practice Standards and associated Quality Indicators through a third-party audit. These processes are intended to be of value for providers, with a focus on support delivery and quality improvement. However, we have heard that these processes can be burdensome and do not necessarily contribute to improvements in support delivery, instead focusing on a provider's paperwork, policies and procedures (see Sections 3.1.4 and 4.2.2). This further undermines the perceived value of registration.

> *"Preparing for registration audits, mid-term audits and re-registration is time consuming, costly and distracting from our core work."– SDN Children's Services[2263]*

Particular concerns around regulatory burdens arise for the many NDIS providers who do – or are able to – work across the wider care and support sector, such as in aged care, non-NDIS disability support delivery, and allied health. Cross-sector providers are subject to other regulatory or professional registration requirements – such as the Aged Care Quality and Safety Commission, which regulates aged care providers, or the Australian Health Practitioner Regulation Agency (AHPRA), which oversees professional registration of some allied health practitioners.[2264] We know that meeting these various regulations and requirements across the wider sector can be duplicative and costly for providers.[2265]

We have received a number of submissions that point to specific issues of duplication in NDIS regulation. This includes:

* Overlap and duplication with standards and compliance obligations under the Aged Care Quality and Safety Commission.
* Reporting under the National Regulatory System for Community Housing for Specialist Disability Accommodation providers.
* Instances where professional scope of practice is already regulated (for example, AHPRA requirements).
* Some standards under the Australian Commission on Safety and Quality in Health Care.[2266]

> *"It is extremely important to note that not all unregistered NDIS providers are equal in terms of the regulatory environment in which they operate. For some providers, the absence of NDIS registration doesn't mean absence of regulation. As explained above, physiotherapy is a highly-regulated profession. Many other allied health professionals operate in an Ahpra [Australian Health Practitioner Regulation Agency]-regulated or self-regulated environments" – Australian Physiotherapy Association[2267]*

On the other hand, other regulatory systems may not consider all the elements that have been identified as important to work in NDIS markets – for example, attitudes and approaches expected when working with people with disability outlined in the NDIS Practice Standards, such as a focus on person-centred supports, informed choice and individual values and beliefs.[2268]

Wherever possible, NDIS regulation should be streamlined and work alongside other formal regulation to reduce excessive burden and costs for providers, without diminishing standards of quality and safety in the NDIS.

3.1.7.   Current NDIS Practice Standards do not sufficiently reflect the diversity of supports in the market, resulting in a lack of clarity about the expectations and obligations of providers

The NDIS Practice Standards and associated Quality Indicators set clear expectations for providers on their role and outcomes that should be met in the delivery of supports.[2269] They also support participants to understand what they should expect from providers. The NDIS Practice Standards include:

- General standards and outcomes that are relevant in the delivery of many supports – known as the 'Core Module' for more complex supports and the 'Verification Module' for less complex supports. These cover issues such as rights and responsibility for participants, a provider's governance and operational management, and the provision of supports by a provider.
- Additional standards and outcomes that are specific to the delivery of certain types of supports – with support-specific standards for high intensity daily personal activities, early childhood supports, specialised support coordination, specialist behaviour support, implementing behaviour support plans, and specialist disability accommodation'.

However, there are a range of support types that do not have specific standards but would likely benefit from the articulation of more specific expectations and outcomes in NDIS Practice Standards. This includes intermediary or advisory supports such as current Support Coordination and the recommended Navigator function, and supported independent living or 24/7 living supports. The NDIS Commission has recently committed to developing NDIS Practice Standards for supported accommodation following its Own Motion Inquiry into Aspects of Supported Accommodation.[2270]

Furthermore, the NDIS Practice Standards have not been updated to respond to new supports and delivery models. The NDIS market looks very different to what was initially envisioned, in particular with growth in intermediary supports and the introduction of new supports like platform providers.[2271] However, the NDIS Practice Standards have not been updated in response. For example, psychosocial recovery coaches were introduced in 2019-20 to support participants with psychosocial disability, however no Practice Standard has been developed to set expectations for the delivery of this support.[2272] Similarly, a Practice Standard has not been developed in response to the growth in a diverse range of platform provider models.

We have also received submissions raising the need for additional and updated standards that better reflect the diversity of supports available. In particular, this feedback has focused on intermediary supports, due to confusion around roles and responsibilities for providers.

> *"Greater clarity is required on the roles and responsibilities of all the key actors including that of intermediaries (e.g. Support Coordinator) and the wider community."*
> *– Life Without Barriers[2273]*

"A review of regulations for plan management and support coordination registration requirements should also be prioritised...[would]...help to alleviate risk of participant safety, and ensure intermediaries are held to a higher standard for the quality of services provided." – NIB Thrive[2274]

It is critical for providers to have clear expectations, outcomes and responsibilities, so that they know what should be achieved as part of support delivery and what their regulatory obligations are. Providers should be required to demonstrate their compliance with NDIS Practice Standards and other requirements relevant to the supports they deliver as part of the registration process. NDIS Practice Standards that better cover the diversity of supports delivered in the market will support efforts to prevent harm and drive quality in supports by setting clear, consistent expectations and outcomes for providers.

3.1.8. A new model of regulation must strike a better balance with appropriate and risk-proportionate oversight of the whole market, while reducing burdens and duplication where possible

We recognise choice and control as a central principle of the NDIS, and that the safety of people with disability is paramount. Currently, regulatory and registration requirements are largely determined by the way in which a plan is financially managed, which is leading to high-risk supports being delivered with little regulatory oversight. A better balance is required to ensure the effective prevention of harm, while also supporting people with disability to purchase supports of their choosing and have control over the way in which these supports are delivered.

We are proposing greater use of preventative measures applied to all providers and participants to make the system work better for everyone and prevent harm to those most at risk. We need to strike a better balance between preventing harm, supporting choice and control, encouraging innovation and enabling the market to thrive.

To prevent harm and better ensure the delivery of safe and quality supports, the new National Disability Supports Quality and Safeguards Commission should apply a graduated and risk-proportionate approach to the regulation of the whole provider market, including foundational supports. This would ensure the new National Disability Supports Quality and Safeguards Commission can be more proactive in preventing harm, while also supporting efforts to strengthen scheme integrity.

To achieve this, we recommend a new graduated and risk-proportionate regulatory model for provider regulation (summarised in Figure 161 below). This model includes requirements for providers to be registered or enrolled depending on the risk and complexity of their activities and operations. It also detaches provider regulatory requirements from the financial management of individual budgets. This means that the way a participant's budget is financially managed will not determine regulatory requirements, with registration or enrolment requirements being determined by the risk of a provider's activities and operations. In developing this model, we have considered the graduated regulatory model proposed in aged care, in order to support a more streamlined

experience for providers operating in both sectors and regulatory harmonisation efforts over time (see Section 6.1.4).[2275]

The recommended new graduated and risk-proportionate regulatory model is based around four broad categories related to the risk associated with different types of supports and providers, with corresponding risk-proportionate mandatory registration or enrolment requirements.

- **Advanced registration for all high-risk supports,** applying more intensive regulatory requirements and oversight where supports may pose an inherently high-risk or require a high-level technical competence.
- **General registration for all medium-risk supports,** applying graduated approaches to regulatory requirements and oversight, depending on factors impacting the level of risk.
- **Basic registration for lower-risk supports,** applying lighter-touch registration requirements, while still allowing for regulatory oversight against Practice Standards, when required.
- **Enrolment of all providers of lowest-risk supports,** providing full visibility of the market and applying lightest-touch requirements.

Where a provider delivers a range of supports with varying risk profiles, the registration category and requirements will be determined by the highest-risk type of supports the provider is delivering. However, there will be proportionality in the auditing and assessment requirements applied to the provider based on the range of supports delivered – for example, with more intensive auditing applied in respect of high-risk supports delivered by the provider, while accepting self-assessment and attestation of compliance in respect of lower-risk supports.

This approach to preventing harm should promote safe and effective support delivery, without imposing undue barriers, burdens or duplication. Providers should be required to meet requirements that are commensurate to the risk of their activities and operations. These processes should be integrated with other government systems and recognise similar compliance of providers operating in other parts of the care and support sector. This will guard against regulatory creep, ensure proportionality, and minimise unnecessary burdens.

Figure 161: Graduated and risk-proportionate regulatory model

Provider obligations

	A. Advanced registration — In-depth registration for high-risk supports	B. General registration — Graduated registration for medium-risk supports	C. Basic registration — Light-touch registration for lower-risk supports	D. Enrolment — Basic visibility and requirements for lowest-risk supports
Code of Conduct	YES	YES	YES	YES
Worker screening (Action 17.4)	YES · Workers in risk-assessed roles.	YES · Workers in risk-assessed roles.	YES · Workers in risk-assessed roles.	YES · Workers directly delivering specified supports or services, or who have more than incidental contact with people with disability.
Subject to complaints process	YES	YES	YES	YES
Report incidents	YES	YES	YES	NO
Practice Standards	YES · General standards and support-specific standards for all support types.	YES · General standards for all support types and support-specific standards where needed.	YES · Simplified general standards for all support types.	NO
Performance measurement (Action 12.3)	YES	YES	YES	NO

Processes

	A. Advanced registration	B. General registration	C. Basic registration	D. Enrolment
Application, identity verification and Code of Coduct and worker screening attestation	YES · Provider completes online application form, integrated with centralised online platform and NDIS payments system (Actions 10.1 and 10.3) to provide the NDIA and new National Disability Supports Quality and Safeguards Commission with visibility of all providers and data on payments. · Application form collects basic information (e.g. business name, ABN or Digital ID, bank account details, location, contact details, support types delivered). · Business identity is verified leveraging existing government systems and processes (such as myGovID). · Provider attests to understanding obligations under code of conduct and worker screening requirements.			
Audit of compliance with Practice Standards	YES · In-depth observational audit of compliance with relevant practice standard. · Streamlining where appropriate based on risk, such as the use of desktop auditing, self-assessment and attestation, and mutual recognition of compliance in other regulatory systems.	YES · Graduated and proportionate audit of compliance with relevant practice standards, including observational and/or desktop auditing. · Streamlining where appropriate based on risk, such as the use of self-assessment and attestation, and mutual recognition of compliance in other regulatory systems.	NO · But includes a self-assessment and attestation of compliance with Practice Standards, in place of an audit.	NO
Suitability assessment of provider and key personnel	YES	YES	YES	NO
Ongoing monitoring and compliance	YES The National Disability Supports Commission undertakes: · Risk-based monitoring, investigation and regulatory intelligence gathering (including through provider outreach and information sharing with other regulators). · Corrective action in response to breaches of the code of conduct (registered and enrolled providers) and practice standards (registered providers only).			

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As part of this model, the new National Disability Supports Quality and Safeguards Commission should have the power to refuse and revoke registration, as well as revoke enrolment, if it is concerned that a provider is a risk to people with disability, the integrity of the NDIS or other disability supports. This may include instances where a provider has previously committed fraud or has been subject to regulatory action in other sectors. To support this, registration and enrolment processes should be integrated with other government systems such as myGovID to provide more robust business identity verification. Alongside this, efforts should be made to streamline and speed up the suitability assessment process to reduce overall processing times for registration.

Further work will be required to design and implement this model, including consultation with people with disability, providers and other regulators. This should include the development of a Provider Risk Framework to identify and evaluate the risk profile of different types of supports and providers, the development of new or amended general and support-specific Practice Standards, and the development and implementation of flexible approaches to auditing and assessing compliance. This should also include integration of the model with a centralised online platform (see Action 10.1) and NDIS payment systems (see Action 10.3).

Figure 162 outlines steps in the registration and enrolment processes, and how these processes could be integrated with the centralised online platform and NDIS payments systems.

Figure 162: Registration and enrolment process

Registration and enrolment process

STEPS 1 and 2: Provider completes an online application form via the centralised online platform and nominates the types of supports they are intending to deliver for participants.

Provider is intending to deliver **high-risk supports.**

Provider is intending to deliver **medium-risk supports.**

Provider is intending to deliver **lower-risk supports.**

Provider is intending to deliver **lowest-risk supports.**

STEP 3: Provider **attests to understanding obligations** under the Code of Conduct and worker screening requirements.

Provider is directed to complete the registration process, with requirements proportionate to risks of their activities and operations based on the Provider Risk Framework.

STEP 4A: Advanced Registration.

- **In-depth observational audit** by third-party auditor against general and support-specific Practice Standards.

- Streamlining where appropriate based on risk, such as the use of desktop auditing, self-assessment and attestation, and mutual recognition of compliance in other regulatory systems.

STEP 4A: General Registration.

- **Graduated and proportionate audit** by third-party auditor, involving observational and desktop auditing, against general (all) and support-specific (where needed) Practice Standards.

- Streamlining where appropriate based on risk, such as the use of self-assessment and attestation, and mutual recognition of compliance in other regulatory systems.

STEP 4A: Basic Registration.

- **Attestation only (no audit required)** where providers self-assess and attest to compliance with simplified general Practice Standards.

STEP 4: Provider is enrolled.

- Provider is directed to information and resources on being a provider, including insurance, tax and business resources.

STEP 4B: Suitability assessment: National Disability Supports Commission has the power to refuse or revoke registration.

STEP 4C: Provider is registered.

STEP 5: Back-end data-sharing across NDIS systems: Relevant provider information is **published on the online platform** (so participants can search for providers using filters), **shared to the NDIS payments system** (so participants can pay providers), and **used to inform coordinated scheme integrity measures.**

ONGOING: National Disability Supports Commission undertakes **risk-based monitoring, investigation and regulatory intelligence gathering** (including through provider outreach and information sharing with other regulators), and **corrective action in response to breaches** of the Code of Conduct (registered and enrolled providers) and Practice Standards (registered providers only).

Treatment of providers in this model

While further work will be required to develop a Provider Risk Framework and evaluate the risk profiles of different supports and providers to inform their treatment in this new graduated and risk-proportionate regulatory model, we have provided indicative examples in Box 91 below.

Box 91: Examples of how some supports or providers may be treated under the recommended new graduated and risk-proportionate regulatory model

The Review anticipates that most providers and supports will be subject to Basic or General Registration, unless there is sufficient evidence and regulatory intelligence to support more intensive registration requirements.

High-risk supports, with providers required to undergo Advanced Registration, may include:

- Current mandatory registration categories, such as behavior support planning, implementation of restrictive practices and specialist disability accommodation.
- Supports delivered in high-risk settings, such as daily living supports delivered in formal closed settings (such as group homes).
- Some directly commissioned supports where the nature of the support presents relatively higher risks, such as Navigators (see Recommendation 4) and Lead Practitioners (see Recommendation 6) that have significant influence over decision-making.
- Providers of early intervention early childhood supports that are critical to the meeting of developmental milestones and outcomes (see Recommendation 6).

Medium-risk supports, with providers required to undergo General Registration, may include:

- Some larger organisations, where this may increase the complexity of governance and supervision of provider activity.
- High intensity supports (such as high intensity daily personal activities) and supports that require additional skill and training (such as complex bowel care or injections).
- Supports that involve significant 1:1 contact with people with disability.
- Some directly commissioned supports, where the nature of the supports presents relatively lower risks.

Lower-risk supports, with providers required to undergo Basic Registration, may include:

- Some sole traders and smaller organisations, where size of the provider may decrease the complexity of provider activity.
- Supports delivered in lower-risk settings or involving more limited 1:1 contact with people with disability, such as community participation activities and some group and centre-based activities.

- Supports that are specialist but present relatively low risks, such as specialist accessible transport or providers that specialise in household tasks for people with disability.

Lowest-risk supports, with providers required to undergo Enrolment, may include:

- Supports delivered in low-risk settings and with limited participant contact, such as home and vehicle modifications.
- Supports where general protections available under Australian Consumer Law are sufficient, such as consumables, equipment and technology, in addition to any home and vehicle modifications.
- Other generally available and non-specialised services, such as general transport, gardening and cleaning services, where providers are not providing a service that is specialised for people with disability.

The implementation of the new model will also require some flexibility to account for the diversity of support delivery models in the market and ensure no disruptions in support delivery for people with disability. However, while flexibility in the application of the model should be provided, this should not lead to exemptions and exceptions in order to ensure full visibility of the market and support effective and consistent safeguarding. Particular instances requiring further consideration of the appropriate application of the model include:

- The need for greater support for providers delivering culturally appropriate and safe supports to enter and operate in the market, such as for culturally and linguistically diverse and First Nations people with disability (including in rural and remote areas). This should include actively supporting providers to become registered where barriers to registration are identified.
- The treatment of different models of platform provider service provision.

  - All platform providers should be included in the new graduated and risk-proportionate regulatory model. However, to account for the differing models of platform provider service provision, specific requirements to register should be determined based on the business structure, the services provided, the nature of the relationship between the platform provider and individuals delivering supports, and the nature of interactions and commitments between the platform provider and people with disability.

  - Subject to further consultation and design (as well as any broader consideration by government of policy and legislative settings for digital platforms), we suggest that:

    o At a minimum, all platform providers should be subject to registration requirements as a provider of platform/intermediary services, supported by appropriate Practice Standards.

    o If a platform provider employs individuals delivering supports, the platform should be considered the provider of these supports and be subject to the relevant registration or

enrolment requirements as a provider of direct supports (in addition to requirements as a provider of platform/intermediary services).

- o If a platform provider does not employ individuals delivering supports, these individuals should be considered sole trader providers and be subject to relevant registration or enrolment requirements (with the platform only subject to requirements as a provider of platform/intermediary services).

- o Factors that may influence the treatment of different models and structures include the nature of any direct relationships, interactions and commitments between the platform provider and people with disability (such as representations to people with disability about the standards and quality of individuals delivering supports via the platform); and/or the extent to which the relationship between the platform and individuals delivering supports is employee-like. For example, subject to further design and consultation, the Review considers that General Registration would be appropriate for platforms that make representations and provide assurances to people with disability about the standards and quality of individuals delivering supports; whereas Basic Registration would be appropriate for platforms that only provide infrastructure and 'back-office support' for providers to connect with people with disability.

- The treatment of circumstances where participants directly employ their workers, including Services for One arrangements where families may directly employ workers to deliver supports.

  - We note that legal arrangements and relationships may vary in circumstances where participants directly employ their workers. Close consultation with this group will be necessary to determine the appropriate treatment of these arrangements.

  - We note that Services for One arrangements have generally been set up in circumstances where the support needs of the participant are very complex and families have not been able to obtain the quality of supports they require in the open market. Close consultation with this group will be particularly important, so as not to disrupt arrangements which are working well and have taken years to establish and build up.

Proportionality in this model

A critical component of this model is ensuring regulatory requirements, processes and oversight are proportionate to the risk and complexity of a provider's activities and operations, while guarding against regulatory creep. This is necessary to address existing issues of burden and duplication, and ensure that the right balance is struck between appropriate regulation to prevent harm without imposing excessive burdens and costs on the market. A balance must also be struck between maintaining proportionality and avoiding regulatory creep, while also responding to systemic or individual issues of risk – for example, to adjust the categorisation and requirements for a particular type of support in response to evidence of systemic risk or harm, or to adjust requirements at the individual provider level in response to regulatory intelligence.

Further work to determine how and where proportionality should be applied will be required as part of designing and implementing this model. However, we have identified some levers that could be used to introduce greater proportionality and streamlining in the implementation of this

model (see Box 92) – including through simplifying Practice Standards where possible, recognising compliance in other similar regulatory systems, using risk-based auditing and assessment approaches, and targeting the scope of audits to the most relevant and important issues. These proportionality approaches should be applied to all levels of registration to ensure that regulatory burden is proportionate to risk.

In particular, more effective and flexible approaches to auditing – alongside efforts to refocus audits on quality (see Section 4.2.2) – will be an important part of introducing greater proportionality. This should include better targeting the scope of audits, and complementing, supplementing or replacing audits with other regulatory tools – for example, using self-assessment and attestation in place of auditing where appropriate, and putting greater focus on monitoring and identifying risk beyond initial audits, including through a new provider outreach function (see Section 4.1) . This should include, mutual recognition of compliance with similar standards in other regulatory systems across the care and support sector (such as in aged care). This is consistent with Recommendation 10.21 of the Disability Royal Commission to remove duplication of requirements for cross-sector providers.[2276]

Box 92: Examples of levers for proportionality in the regulation of providers

- **Simplifying Practice Standards**, including developing simplified Practice Standards for all providers required to undergo Basic Registration, or removing some aspects of Practice Standards for sole trader providers where these standards are more relevant to organisations.
- **Mutual recognition of standards** where providers are delivering similar supports in the wider care and support sector and have demonstrated compliance under other regulatory systems. This may include recognition of similar aged care standards or recognition of professional registration where appropriate (for example, AHPRA registration and requirements).
- **Varying the intensity of and approach to audits** for different categories of registration, including through using hybrid approaches to observational and desktop audits, using self-assessment and attestation as evidence of compliance, and/or making greater use of ongoing monitoring (such as provider outreach) to supplement, complement or replace auditing.
- **Targeting audit scopes more tightly** based on the particular circumstances of individual providers, including focusing on certain aspects of Practice Standards most relevant to a provider's activity or where higher risk is identified, while accepting attestation as evidence of compliance with other aspects of Practice Standards.

Implementing this model

We know moving to this new graduated and risk-proportionate regulatory model – covering the whole provider market and applying to all participants – will be a significant change for providers

and participants. However, the NDIS is a system that delivers a wide range of supports, and supports a wide range of participants who have varying capacities to manage risks independently in their lives. As noted earlier, we are proposing greater use of preventative measures applied to all providers and participants, rather than more specific differentiation. This will make the system work better for everyone, remove unnecessary complexity, reduce inconsistency in regulation between registered and unregistered providers, and avoid the creation of potential gaps in which harm could occur without appropriate regulatory oversight.

We also know that such a significant change will require a period of sequenced and staged transition, supported by measures to ensure providers are prepared to transition to new regulatory requirements. This should include:

- Sequencing transition by starting with the expansion of Advanced Registration requirements to additional high-risk supports first, and transitioning all currently unregistered providers to Enrolment before subsequently transitioning to General and Basic Registration requirements where appropriate.
- Developing significant changes to legislation, ICT systems and regulatory processes in order to implement this.
- Integrating regulatory processes with the centralised online platform and NDIS payments systems (see Actions 10.1 and 10.3), as well as whole-of-government systems such as myGovID, so that providers do not have to complete multiple processes and be required to provide similar information.
- Providing strong communication, engagement and support for providers to enable a smooth transition to new regulatory requirements, with particular focus given to ensuring implementation of these requirements does not exacerbate thin market issues.

The implementation of this model will need to be supported by an appropriately resourced new National Disability Supports Quality and Safeguards Commission that is proactive, responsive and risk-based in its approach to the regulation of the market (see Action 19.3). To support effective implementation of this model, it will also be important that NDIS price caps reflect the market price for delivering supports – including any costs associated with regulation. This should be ensured through the recommended new pricing and payments regulatory framework (see Recommendation 11).

3.1.9. New supports and functions proposed in the Review's other recommendations must be integrated into this regulatory model to ensure consistent oversight, quality and safeguarding

We are proposing a range of new supports and functions, which will be delivered in different ways (for example, some directly commissioned, while others funded through individual budgets). New functions and supports include Navigators and Specialist Navigators (see Recommendation 4), Lead Practitioners (see Recommendation 5), psychosocial disability specific providers (see Recommendation 7), new foundational supports (see Recommendation 1), and other new types of advisory and decision-making support (see, for example, Actions 5.3 and 8.4). New methods of

support purchasing, commissioning and delivery include providers who deliver supports in First Nations communities and remote communities under alternative commissioning approaches (see Recommendation 14) and providers who are part of provider panel or preferred provider arrangements (see Actions 13.2 and 11.2).

It is critical that all new supports are integrated into the recommended new graduated and risk-proportionate regulatory model, including through the development of new Practice Standards to detail expectations for the delivery of these supports. This will ensure consistent regulatory oversight, deliver effective safeguarding of people with disability regardless of the types of supports they are accessing, and avoid confusion for both providers and people with disability about how supports are regulated and who is responsible. In addition to quality and safeguarding requirements set through the regulatory framework, some providers may also need to meet additional service delivery requirements to deliver supports under different settings for market access (see Chapter 4).

Implementation of this model will also address a challenge we have observed in current arrangements, whereby some supports that are commissioned and delivered under contractual arrangements are regulated inconsistently with other supports. For example, Local Area Coordinators are contractors of the National Disability Insurance Agency (NDIA) and currently regulated through service contracts rather than by the NDIS Commission, causing confusion for providers and participants.

3.1.10. Action & Implementation Details

📄 **Action 17.1: The <u>Department of Social Services</u> and the new <u>National Disability Supports Quality and Safeguards Commission</u> should design and implement a graduated risk-proportionate regulatory model for the whole provider market**

This should be developed in consultation with people with disability, providers and other regulators. The model should include mandatory registration or enrolment of all providers, with requirements proportionate to the risks of a provider's activities and operations. This should provide full visibility of the market, incorporate requirements that are more finely tuned to risk, and address gaps, excessive burdens and duplication in current requirements. New supports and functions proposed in other recommendations (including Navigators, Lead Practitioners and foundational support providers) should be regulated under this model to ensure appropriate safeguarding of people with disability and avoid creating gaps in regulation. The implementation of this model should be informed by the development of a provider risk framework that identifies and evaluates the risk profile of different types of supports and providers.

Implementation detail:

- The Department of Social Services (DSS) and the new National Disability Supports Quality and Safeguards Commission should design and implement a graduated, risk-

proportionate model of provider regulation. The model should comprise four broad categories for registration or enrolment, each with different obligations and requirements. The treatment of different supports and providers should be informed by development of a Provider Risk Framework (see below).

- Mandatory advanced registration for all high-risk supports, applying more intensive regulatory requirements and oversight where supports may pose an inherently high-risk or require high-level technical competence.

  o Obligations: Providers should be required to comply with the Code of Conduct and relevant Practice Standards (both general standards and support-specific standards in all cases); ensure worker screening of all workers in risk assessed roles; and report incidents to the new National Disability Supports Quality and Safeguards Commission. Providers should also be subject to performance measurement (see Action 12.3).

  o Processes: Providers should be required to demonstrate compliance with relevant Practice Standards through in-depth observational audits by third-party auditors, with a focus on the quality of support delivery and the experience of people with disability.
  There should be some flexibility for providers to self-assess and attest to compliance with some requirements (for example, paperwork, policy and procedure requirements); as well as some mutual recognition of compliance with comparable general standards in other systems (for example, aged care) or professional registration compliance (for example, AHPRA registration and requirements) wherever possible. The new National Disability Supports Quality and Safeguards Commission should also undertake a suitability assessment as part of registration.

- Mandatory general registration for all medium-risk supports, applying graduated approaches to registration requirements, depending on factors impacting the level of risk.

  o Obligations: Providers should be required to comply with the Code of Conduct and relevant Practice Standards (both general standards in all cases and support-specific standards where needed); ensure worker screening of all workers in risk assessed roles; and report incidents to the new National Disability Supports Quality and Safeguards Commission. Providers should also be subject to performance measurement (see Action 12.3).

  o Processes: Providers should be required to demonstrate compliance with relevant Practice Standards in a graduated and proportionate way. This may include the use of a third-party auditor to assess some aspects of compliance (with observational and/or desktop audits used depending on circumstances); allowing providers to self-assess and attest to compliance with some requirements (for

example, paperwork, policy and procedure requirements); and using hybrid approaches that combine third-party audit and self-assessment and attestation. There should also be mutual recognition of compliance with comparable general standards in other systems (for example, aged care) or professional registration compliance (for example, AHPRA registration and requirements) wherever possible. The new National Disability Supports Quality and Safeguards Commission should also undertake a suitability assessment as part of registration.

- Mandatory basic registration for lower-risk supports, applying lighter-touch registration requirements, while still allowing for regulatory oversight against Practice Standards, when needed.

  o Obligations: Providers should be required to comply with the Code of Conduct and simplified general Practice Standards; ensure worker screening of all workers in risk assessed roles; and report incidents to the new National Disability Supports Quality and Safeguards Commission. Providers should also be subject to performance measurement (see Action 12.3).

  o Processes: Providers should be required to self-assess and attest to compliance with their obligations and requirements under the Practice Standards, in place of auditing. The new National Disability Supports Quality and Safeguards Commission should also undertake a suitability assessment as part of registration.

- Mandatory enrolment of all providers of lowest-risk supports, providing full regulatory visibility of the whole market and applying lightest-touch requirements.

  o Obligations: Providers should be required to comply with the Code of Conduct; and ensure worker screening of workers where normal duties either include the direct delivery of specified supports or services to people with disability or are likely to require more than incidental contact with people with disability.

  o Processes: Providers should provide basic information (for example, business name, ABN or Digital ID, bank account details, location, contact details, and support types delivered) through an online application form. As part of this, providers should be required to attest that they understand their obligations under the Code of Conduct and worker screening requirements.
  This process should leverage existing government ICT systems and processes (such as myGovID) to draw on business information already provided and provide more robust business identity verification (see Recommendation 10).

- DSS and the new National Disability Supports Quality and Safeguards Commission should develop a Provider Risk Framework to identify and evaluate the risk profile of different types of supports and providers. This should be developed through extensive consultation with people with disability, providers and other regulators.

- This Framework should be used to inform the treatment of different types of supports and providers in the model and guide how risk-proportionate features of regulatory

oversight are applied. In applying the Provider Risk Framework, the new National Disability Supports Quality and Safeguards Commission would also need to take account of the specific characteristics of particular providers and available regulatory intelligence.

- This Framework should take account of a broad range of factors and indicators of risk, including:

    - Indicators of high inherent risk in support delivery, such as:

        o Where supports are delivered in a formal setting with limited informal supports (for example, people with disability in group homes);

        o Where a person's choice in the support and provider is constrained (for example, through direct commissioning of supports);

        o Where a provider is in a position to exert influence over a person's choices (such as supporting decision-making, connecting people with disability with support or managing funding); and

        o Where early intervention supports are delivered to children and will affect long-term development or long-term reliance on the NDIS.

    - Further indicators that may increase or decrease the risk of a support or provider, such as:

        o The intensity of a support (for example, whether it involves more specialist or health-related supports);

        o The setting in which a support is being delivered (for example, risk may differ for supports delivered in a person's home versus in the community);

        o The level of contact with a person (particularly on a 1:1 basis versus supports delivered in a group);

        o The size of the provider (for example, larger providers versus smaller or sole trader providers); and

        o Regulatory intelligence gathered through market monitoring or information sharing with other regulators about a particular provider or systemic risk of some support types.

- DSS and the new National Disability Supports Quality and Safeguards Commission should undertake the following activities, and have regard to the following considerations, to inform the development and implementation of this model:

    - Proportionality and mutual recognition should be applied wherever possible to avoid excessive burdens and duplication with other regulation in the care and support sector. Intensive requirements should not be applied as a default. It is anticipated that most supports should require Basic or General Registration, unless there is sufficient evidence and regulatory intelligence to support more intensive requirements.

    - Registration and enrolment application forms and processes should be integrated with other systems. All providers, regardless of whether they are undergoing

registration or enrolment, should be required to complete an application form and attest to understanding their obligations under the Code of Conduct and worker screening requirements as an initial step. Application forms and processes should leverage existing government ICT systems and processes (such as myGovID) to draw on business information already provided and provide more robust business identity verification. They should also be integrated with the centralised online platform (see Action 10.1) and NDIS payments systems (see Action 10.3).

- New or amended Practice Standards that better reflect the breadth and risk of different types of supports and providers should be developed to set appropriate standards and provide clear expectations for providers, including expectations around upholding the rights of people with disability in line with the UN Convention on the Rights of Persons with Disabilities. In the first instance, this should include filling existing gaps in standards (such as for platform providers and intermediaries), and developing simplified standards for use in Basic Registration. Beyond this, there should be ongoing efforts to develop and revise Practice Standards as the market evolves.

- The new National Disability Supports Quality and Safeguards Commission should have flexibility in determining the most appropriate auditing or assessment approaches for different circumstances, including to reduce reliance on point-in-time formal auditing where appropriate. This should occur alongside efforts to refocus audits on improving the quality of support delivery (see Action 12.2). Flexibility should include considering:

  o Where independent third-party auditing should be used versus where in-house auditing may be appropriate, or where no audit is required and attestation could be used instead.

  o Approaches for risk-based auditing and assessment of providers delivering a range of supports with varying risk profiles. For example, more intensive auditing should be applied in respect of higher-risk supports, while accepting self-assessment and attestation of compliance in respect of lower-risk supports.

  o The appropriate duration of registration and enrolment, and what any renewal process should involve. Registration renewal may need to be more frequent for Advanced Registration than General and Basic Registration. Auditing and assessment processes for registration renewal should be targeted to risk and changes, rather than reassessing all aspects of a provider's activities and compliance. Enrolled providers could also be require to re-attest to understanding their obligations on a regular basis (for example, once every three years).

  o How audit teams are staffed, utilising a range of technical and consumer experts, third-party auditors, and new National Disability Supports Quality and Safeguards Commission staff (see Action 12.2).

- Where provider outreach activities (see Action 12.1) can be used to complement, supplement or replace auditing where appropriate, reducing the focus on auditing at the initial registration point in favour of more ongoing monitoring and supervision.

- Flexibility in the application of the model must also remain to respond to systemic issues of risk (for example, to adjust the categorisation and requirements for a particular type of support). Similarly, there should be flexibility to adjust requirements and/or categorisation at the individual provider level in response to regulatory intelligence about risk. However, other regulatory tools (such as provider outreach and compliance activities) should be utilised in the first instance to monitor and respond to concerns about individual providers.

- The new National Disability Supports Quality and Safeguards Commissioner should have the power to refuse or revoke registration, or revoke enrolment, if it is not satisfied that a provider is not a risk to people with disability, the integrity of the NDIS or other disability supports.

- Improvements should be made to the suitability assessment undertaken by the new National Disability Supports Quality and Safeguards Commission to determine whether to register a provider. This should include process improvements and automation to streamline and speed up this assessment process and reduce overall processing times for registration. Consideration should also be given to situations where some providers could be granted conditional registration while the suitability assessment is being undertaken (for example, for Basic Registration). This would remove delays for lower-risk providers being able to operate in the market.

- All providers should be subject to risk-based oversight, monitoring and regulatory action. This is a critical element of a risk-proportionate approach. This should include regulatory intelligence gathering and analysis (including through complaints, incident reporting and information sharing with other regulators); risk-based monitoring and investigation activity; use of new regulatory tools such as provider outreach to identify and respond to quality and safety issues identified in monitoring; and compliance activities in response to breaches of the Code of Conduct (for registered and enrolled providers), as well as the Practice Standards (for registered providers only).

- Consideration should be given to the diversity of supports and providers in the market, and where flexibility may be required in the model. Circumstances where flexibility may need to be considered include:

  - Culturally appropriate and safe providers: Registration and enrolment processes should be inclusive of providers who are delivering culturally safe supports to diverse populations, such as to culturally and linguistically diverse and First Nations people with disability (including in rural and remote areas). Processes

should be scrutinised to ensure they do not include cultural biases and provide active support for these providers to register or enrol where appropriate.

o Platform providers: All platform providers should be included in the new graduated and risk-proportionate regulatory model. However, to account for the differing models of platform provider service provision, specific requirements to register should be determined based on the business structure, the services provided, the nature of the relationship between the platform provider and individuals delivering supports, and the nature of interactions and commitments between the platform provider and people with disability (such as representations to people with disability about the standards and quality of individuals delivering supports via the platform). Subject to further consultation and design (as well as any broader consideration by government of policy and legislative settings for digital platforms), the Review suggests that:

o At a minimum, all platform providers should be subject to registration requirements as a provider of platform/intermediary services, supported by appropriate Practice Standards.

o Subject to any broader consideration by governments on policy and legislative settings for digital platforms:

  o If a platform provider employs individuals delivering supports, the platform should be considered the provider of these supports and be subject to the relevant registration or enrolment requirements as a provider of direct supports (in addition to requirements as a provider of platform/intermediary services).

  o If a platform provider does not employ individuals delivering supports, these individuals should be considered sole trader providers and be subject to relevant registration or enrolment requirements (with the platform only subject to requirements as a provider of platform/intermediary services).

  o Factors that may influence the treatment of different models and structures include the nature of any direct relationships, interactions and commitments between the platform provider and people with disability; and/or the extent to which the relationship between the platform and individuals delivering supports is employee-like. For example, subject to further design and consultation, the Review considers that General Registration would be appropriate for platforms that make representations and provide assurances to people with disability about the standards and quality of individuals delivering supports; whereas Basic Registration would be appropriate for platforms that only provide infrastructure and 'back-office support' for providers to connect with people with disability.

o Situations where a person directly employs workers, including Services for One arrangements: The Review suggests, subject to further close consultation and design, that in these instances workers should be treated as sole trader providers

and be subject to the relevant registration or enrolment requirements. Consultation and design should consider the different legal arrangements and relationships in place, and avoid disruption to these arrangements, which have often taken a significant amount of time to establish.

- The new National Disability Supports Quality and Safeguards Commission should take the following approaches to incorporate new functions and supports recommended by the Review into the new graduated and risk-proportionate regulatory model:

  - All Navigators (see Recommendation 4, Action 7.1 and Action 8.2), as well as Shared Support Facilitators (see Action 8.4), should be required to register with the new National Disability Supports Quality and Safeguards Commission and comply with registered provider obligations. Navigators should be required to demonstrate compliance with general and support-specific Practice Standards, and ensure all workers in risk-assessed roles have an NDIS Worker Screening Check. In addition, any specific service delivery requirements should be stipulated in the funding and contractual arrangements for these supports.

    o Appropriate Practice Standards will need to be developed to reflect expectations of these functions, accounting for general and specialist navigation such as additional housing and living or psychosocial disability service offerings. This should include ensuring Navigators operate within their scope of competency and expertise in delivering different types of navigation support.

  - Lead Practitioners and other Early Childhood providers (see Recommendation 6) should be required to register with the new National Disability Supports Quality and Safeguards Commission and comply with registered provider obligations. These providers should be required to demonstrate compliance with general Practice Standards and the Early Childhood Supports Practice Standard, and ensure all workers in risk-assessed roles have an NDIS Worker Screening Check. In addition, Lead Practitioners should be subject to a service agreement with the NDIA to define specific service delivery requirements.

    o The existing Early Childhood Supports Practice Standard should be strengthened to effectively capture the roles and expectations of Lead Practitioners and other Early Childhood providers, including focusing more on evidence-based and family-centred interventions. In updating the Early Childhood Supports Practice Standard, consideration should be given to, for example, strengthening it by including more detailed evidence-informed quality indicators.

    o This should be undertaken in conjunction with an early focus by the new Deputy Commissioner for Quality (see Action 12.1) on driving quality in the delivery of early childhood supports.

- Providers delivering psychosocial disability specific supports (see Recommendation 7) should be required to register with the new National Disability Supports Quality and Safeguards Commission and comply with registered provider obligations. These providers should be required to demonstrate compliance with general Practice Standards and a support-specific Practice Standard for the delivery of psychosocial disability supports, and ensure all workers in risk-assessed roles have an NDIS Worker Screening Check. In addition, psychosocial-specific early intervention providers should be subject to a service agreement with the NDIA to define specific service delivery requirements.

   o A new support-specific Practice Standard will need to be developed to reflect expectations of these providers. It should set out the additional responsibilities and expectations of providers when providing psychosocial disability specific supports, including workforce competencies and training and expectations of these providers in the delivery of recovery-oriented and trauma-informed supports.

   o Supports that should be in scope for this Practice Standard include Navigators, psychosocial early intervention providers, 24/7 living support providers who support people with psychosocial disability and psychosocial capability-building supports.

   o This should be undertaken in conjunction with an early focus by the new Deputy Commissioner for Quality (see Action 12.1) on driving quality in the delivery of psychosocial supports.

- Foundational Support providers (see Recommendation 1), where funded and commissioned by the Australian Government, should be required to register or enrol with the new National Disability Supports Quality and Safeguards Commission and comply with relevant obligations. Requirements should be commensurate to the risk profile of these supports. For example, some Foundational Supports may be of high, medium, or lower risk and should be registered, whereas other Foundational Supports may be of lowest risk and should be enrolled.

- Independent decision supporters (see Action 5.3) should be required to register with the new National Disability Supports Quality and Safeguards Commission and comply with relevant obligations. Practice Standards that establish expectations specific to the provision of decision-making support will need to be developed.

- Housing and living supports providers (see Recommendation 9) should be required to register or enrol with the new National Disability Supports Quality and Safeguards Commission. Requirements should be commensurate to the risk profile of these supports. For example, 24/7 living supports where providers deliver a high volume of supports to assist people with disability with activities of daily living will present greater risks than drop-in supports for household tasks such as cleaning.

- New or amended support-specific Practice Standards will need to be developed for different housing and living supports. This should include developing a new support-specific Practice Standard for 24/7 living supports and strengthening the Specialist Disability Accommodation Practice Standard to mandate a formal separation between Specialist Disability Accommodation and living support providers (see Action 9.7).

- Supports delivered under different market access settings should be incorporated into the new graduated and risk-proportionate regulatory model. This should include:

  o Providers who deliver supports in First Nations communities and remote communities under alternative commissioning approaches (see Recommendation 14) should be required to register or enrol with the new National Disability Supports Quality and Safeguards Commission, and be actively supported to do so. Requirements should be commensurate to the risk profile of these supports. For example, commissioned supports to assist with daily living in the home will present greater risks than commissioned supports that build community participation. In determining risk-proportionate regulatory requirements, consideration should be given to the fact individuals' choice of support and provider may be constrained.

  o Providers who are part of preferred provider lists (see Action 11.2) or provider panel arrangements (see Action 13.2) should be required to register or enrol with the new National Disability Supports Quality and Safeguards Commission. Requirements should be commensurate to the risk profile of these supports. For example, providers delivering therapy supports under provider panel arrangements will present greater risks than providers delivering capital supports where there are preferred provider lists. In determining risk-proportionate regulatory requirements, consideration should be given to the fact individuals' choice of support and provider may be constrained.

📑 **Action 17.2: The Department of Social Services and the new National Disability Supports Quality and Safeguards Commission should develop a staged implementation approach to transition to the new graduated risk-proportionate regulatory model**

Transition of providers to the new regulatory model (see Action 17.1) should be sequenced and staged, allowing the new National Disability Supports Quality and Safeguards Commission to learn from implementation and make necessary changes and adjustments to support an ongoing smooth transition of the market. Transition should be completed over five years, prioritising some changes early to improve regulatory oversight of high-risk supports and providers, while legislative and systems changes - including integration with

the centralised online platform (see Action 10.1) and payments systems (see Action 10.3) - are developed to support full implementation. It should be accompanied by actions to support providers to transition to new regulatory requirements.

Implementation detail:

- The Department of Social Services (DSS) and the new National Disability Supports Quality and Safeguards Commission should ensure that the implementation approach and transition includes the following key considerations and elements.

  - The development of the Provider Risk Framework (see Action 17.1) and development and passage of amending legislation led by DSS, working with the new National Disability Supports Quality and Safeguards Commission. Development of the Provider Risk Framework will require extensive consultation with people with disability, providers and other regulators. Legislative amendments will include establishing the provider enrolment requirement, removing the link between a participant's financial management of their plan and the regulatory status of their support providers (see Action 17.3), implementing the Provider Risk Framework, and developing or updating Practice Standards. Preparation of amending legislation will also involve further consultation, including with states and territories.

  - Prioritising transition to new arrangements for some providers and simpler legislative amendments under the NDIS Commission's current rule-making powers and in parallel with the development of the Provider Risk Framework. This should include:

    o The design and implementation of Advanced Registration for high-risk supports, to require registration for high-risk supports not in the current mandatory registration categories and develop relevant support-specific Practice Standards.

    o The inclusion of new functions and supports into new graduated and risk-proportionate regulatory model as these functions and supports are established (for example, Lead Practitioners and Navigators), including developing relevant support-specific Practice Standards.

    o Establishing more proportionate audit approaches to assess compliance and quality (for example, more targeted audit scope and exploring opportunities for the use of self-assessment and attestation).

    o Establishing more extensive mutual recognition of compliance with other regulatory systems (such as aged care).

    o Operationalising a provider outreach function to support transition and regulatory oversight across all supports (see Action 12.1).

  - The development of a new or upgraded ICT system for provider enrolment and registration application (in parallel with the actions above). This should be integrated with development of the centralised online platform and NDIS payments systems (see Actions 10.1 and 10.3), and be integrated with a whole-of-Commission uplift in digital

capabilities (see Action 10.4). Development should also ensure linkages and/or integration with existing government ICT systems and processes (such as myGovID).

- A sequenced and staged transition of all other providers to new arrangements. Implementation of General and Basic Registration, as well as enrolment, affects many more currently unregistered providers and is dependent on system builds and upgrades described above. After completion of system builds and upgrades, priority should be given to improving regulatory visibility by initially transitioning all currently unregistered providers (except those required to undergo Advanced Registration) to enrolment, ahead of subsequently transitioning these providers to General and Basic Registration where appropriate over a longer period. This timing and sequencing for this transition to General and Basic Registration should take into account the relative risk of different types of supports and providers.

  o To move currently unregistered providers from enrolment to General and Basic Registration, arrangements should include progressive transition of different cohorts of providers (taking into account relative risk), the application of grace periods for compliance as providers transition to new regulatory requirements, and allowing providers to attest to meeting new requirements prior to undertaking a third-party audit. Any changes for currently registered providers should be aligned with their registration renewal timeframes.

  o The expansion of worker screening requirements (see Action 17.4) should also be staged as part of these transition arrangements.

- Support for providers will be required to assist providers to understand their obligations and ensure a smooth transition that avoids disruption and exacerbation of thin markets wherever possible. Support, engagement and communication with the market should include information resources, education campaigns and an in-house advisory function available to respond to provider inquiries and concerns. The NDIS Commission's Support for NDIS Providers Grants Program should be used to fund projects and activities to develop strategies, resources and online tools to assist providers to transition to the new registration system, including adopting new Practice Standards and building a person-centred, quality-focused culture.

📑 **Action 17.3: The Australian Government should amend the *National Disability Insurance Scheme Act 2013* to remove the link between a participant's financial management of their plan and the regulatory status of their support providers**

The requirement for a provider to either be enrolled or registered, and the intensity of any regulatory requirements, should be determined by the risk and complexity of different supports and providers.

Implementation detail:

- The Department of Social Services should support the drafting and passage of legislation that will remove the link between a participant's financial management of their plan and the regulatory status of their support providers. This should occur in parallel with the development of the new graduated and risk-proportionate regulatory model (see Actions 17.1 and 17.2). It should also be coordinated with other related changes, such as implementation of Navigators (see Recommendation 4).

3.2. Worker regulation and safeguards are inconsistently applied, ineffectively operationalised and can be duplicative for workers across the care and support sector

Workers are critical to safety and quality, and worker screening is an important preventative safeguard to identify workers who may pose an unacceptable risk to people with disability and therefore not be permitted to work in the NDIS.

However, the effectiveness of worker screening is limited by only applying to those working for registered providers. Other challenges exist, with current operationalisation of NDIS worker screening being inconsistent across jurisdictions and at times slow, leading to delays in providers sourcing the workers they need. NDIS worker screening can also be duplicative with other working screening requirements in various jurisdictions and other service systems, which can pose a barrier for some workers joining the NDIS workforce.

While worker screening should be expanded to more workers, this must be supported by improvements to processes and streamlining with other similar checks.

3.2.1. Worker screening is a preventative safeguard but does not apply to all workers delivering supports to people with disability

NDIS worker screening is a preventative safeguarding tool that is designed to assess the risk of individuals working with people with disability, to ensure they do not pose an unacceptable risk of harm.[2277] Where a person does pose an unacceptable risk, they are not granted an NDIS Worker Screening Check and are unable to work for registered providers. NDIS worker screening arrangements commenced in 2021, and over 762,000 individuals have an NDIS Worker Screening Check as at 30 June 2023.[2278]

The NDIS Worker Screening Check involves a number of steps:

- **Application:** A worker applies, through the relevant state or territory worker screening unit, for an NDIS Worker Screening Check once they have been engaged by an employer or an employer intends to engage them in the delivery of NDIS supports. The worker screening unit verifies the worker's identity and collects a service fee, before the application is sent to the NDIS Commission's National Worker Screening Database.

- **Verification:** The NDIS Commission's National Worker Screening Database emails the applicant's nominated employer to confirm their linkage to the worker. Workers must be verified by an employer or organisation delivering NDIS supports or services.[2279]
- **Assessment:** State and territory worker screening units then assess a range of relevant information about applicants, including national criminal history (such as criminal convictions), domestic violence and child protection orders (as well as Apprehended Violence Orders), disciplinary and misconduct information supplied by the NDIS Commission, outcomes of previous NDIS worker screening applications, civil penalties, employer or other professional records/information, and others relevant information (including information from other regulators).[2280] Worker screening units assess whether an individual poses an acceptable or unacceptable risk to people with disability and either grant an NDIS Worker Screening Check or exclude the individual from an NDIS Worker Screening Check (where risk is unacceptable).[2281] The criteria for assessing this risk includes, among others, the nature and gravity of any offences in a worker's criminal history, the length of time that has passed since the event occurred, and the vulnerability of the victim.[2282]
- **Continuous monitoring:** Workers with an NDIS Worker Screening Check are subject to ongoing monitoring for relevant criminal history or NDIS Commission records, or any other information (such as from other regulators) considered relevant by the worker screening unit. This monitoring may lead to reassessment, which may include a suspension by the NDIS Commission while the reassessment is undertaken and possible revocation of an NDIS Worker Screening Check as a result of this reassessment. Independently of this worker screening reassessment, the NDIS Commission can take regulatory action against any NDIS worker (for example, for a breach of the NDIS Code of Conduct) and impose penalties including fines, conditions, or a ban on working in the NDIS market.

Workers who have committed offences such as violence and abuse, or have had regulatory action taken against them by other regulators, may not be able to work for registered providers. Some offences automatically exclude individuals from receiving a Worker Screening Check, while other offences will prompt an assessment by the state or territory worker screening unit of whether the individual poses an unacceptable risk to people with disability in light of their criminal history and other relevant information.[2283]

NDIS worker screening arrangements are designed to be stronger than other screening arrangements, such as Working with Children Checks (WWCC). NDIS worker screening arrangements are national and portable between states and territories, whereas WWCCs are not. NDIS worker screening arrangements also consider broader sources of information than WWCCs, such as civil penalties and relevant workplace misconduct findings, not just convictions. Furthermore, continuous monitoring for WWCCs is limited to offences committed within the relevant state or territory, whereas NDIS worker screening arrangements continuously monitor changes across all states and territories. [2284]

While NDIS worker screening is an effective preventative safeguard, it is only a requirement for workers of registered providers, who must ensure that anyone in a 'risk assessed role' – that is, a

key personnel role, a role involving the direct delivery of specified supports or services to people with disability, or a role requiring more than incidental contact with people with disability – has an NDIS Worker Screening Check.[2285]

Unregistered providers can opt in for worker screening, and self-managing and plan-managing participants can request their workers undergo worker screening. However, take-up has been low, with only 6,467 unregistered providers of more than 154,000 unregistered providers having any workers with an NDIS Worker Screening Check as at 30 June 2023.[2286]

We have heard and observed several inadequacies in the current application of worker screening. Its coverage is limited, with the larger than envisioned unregistered provider market meaning that worker screening requirements only apply to a small proportion of providers. In interviews with 30 self-managing or plan-managing participants and/or plan nominees, Dickinson, Yates and West also observed "most interviewees did not mention any form of screening service so it may not be well understood or utilised".[2287]

> *"Worker screening...only applies to workers for registered providers. As fewer providers register with the NDIS, fewer workers are being screened." – Health Services Union (National)[2288]*

Without a minimum preventative safeguard applying to all workers, the majority of regulatory action with respect to workers is reactive, responding when things have already gone wrong, rather than proactively intervening where a worker may pose a risk of harm or to set clear expectations for all workers.

In addition, the current legislative framework for provider regulation and the application of worker screening means that where a person is assessed as posing an unacceptable risk of harm to people with disability and therefore not granted an NDIS Worker Screening Check (that is, excluded), they can continue to work for unregistered providers, who can be accessed by most participants.

We have also heard of instances of workers – who may otherwise be considered to pose an unacceptable risk of harm to people with disability and therefore be excluded from an NDIS Worker Screening Check – establishing themselves as unregistered providers or working for unregistered providers to avoid worker screening requirements.[2289] This concern has also been raised in submissions we have received.

> *"There is no governance or accountability over independent (non-registered) workers. ...How can the government allow untrained workers to be able to manipulate and work within a system where there is no accountability for them - unless they are caught doing something against the code of conduct - so we then have to wait till a PWD is either taken advantage of, abused, neglected and worse case die before action is taken." – Provider[2290]*

It should be noted that worker screening is only a tool to filter out workers from the market who are known to pose an unacceptable risk to people with disability. It does not establish any

minimum competency requirements or standards for workers, and is not sufficient to guarantee all NDIS workers can deliver safe and quality supports.

All workers, whether screened or not, are required to comply with the NDIS Code of Conduct. Further, registered providers are held to standards in relation to the competencies of their workers through requirements in the NDIS Practice Standards to ensure workers are competent in relation to their role, hold relevant qualifications, and have relevant expertise and experience.[2291] The NDIS Practice Standards are supported by the NDIS Workforce Capability Framework, which provides guidance to explain what this should look like in practice.[2292]

However, we have heard through submissions and other engagement that this lack of minimum safeguards and requirements limits accountability for the quality and safety of workers delivering supports. It also limits the corrective levers that the NDIS Commission has available to respond to misconduct by workers, as well as limiting opportunities to build better capability in the workforce through regulatory requirements.

> *"Currently the role of a support worker/support coordinator does not require anyone to have previous experience, education or training." – Participant[2293]*

3.2.2.   Worker screening requirements should be expanded to more workers, supported by mandatory basic training

Mandatory coverage of the NDIS Worker Screening Check should be expanded as part of the new graduated and risk-proportionate regulatory model (see Action 17.1). This should be achieved by:

- **Registered providers:** All workers in risk-assessed roles should be required to undergo worker screening (consistent with current requirements for registered providers).
- **Enrolled providers:** Workers should be required to undergo worker screening if they are involved in the direct delivery of specified supports or services to people with disability, or if they have more than incidental contact with people with disability. Unlike registered providers, key personnel of enrolled providers should not be required to undergo worker screening.

This expansion of coverage should apply all relevant individuals working for providers regulated by the new National Disability Supports Quality and Safeguards Commission under the new graduated and risk-proportionate regulatory model (see Action 17.1) – whether they are providing NDIS supports or other Australian Government funded disability and foundational supports.

This will ensure workers do not pose an unacceptable risk to the safety of people with disability, while also ensuring that requirements are proportionate to the nature and risk of a provider's activities. This broader coverage will also be more consistent with the approach taken in other human services systems and consistent with Recommendation 10.8 of the Disability Royal Commission to consider an expansion of NDIS worker screening arrangements alongside a national disability support worker registration scheme.[2294]

Submissions we have received have broadly been supportive of expanding worker screening requirements.

> *"Workers for these unregistered providers are not even mandated to undertake Worker Screening Checks, which in our view leaves participant consumers with insufficient guarantees of effective, safe and appropriate services"* – Allied Health Professions Australia[2295]

However, we have also received some submissions raising concerns about impacts on participant choice and control.

> *"If we are of legal age and choose to, we should be allowed to decide exactly the support worker we require, regardless of whether the support worker is formerly trained or registered with the NDIS."* – Participant[2296]

We acknowledge these concerns however, especially in view of the risks to people with disability, we consider them to be outweighed by the benefits of broader application of worker screening.

Expanding worker screening requirements must be supported by efforts to improve the operation of the worker screening process, and to harmonise and streamline worker screening arrangements across different jurisdictions and systems (see Section 3.2.3, Action 17.4 and Action 17.5). Alongside harmonisation of various worker screening arrangements, there should be ongoing evolution of NDIS worker screening to ensure all relevant information and available regulatory intelligence is being used to accurately assess worker risk.

This is consistent with the Disability Royal Commission's Recommendation 10.31 on continuous monitoring of criminal charges, which recommends strengthening NDIS worker screening arrangements to ensure all relevant charges and information is considered and information is effectively shared between states and territories.[2297] It is important to note that this was recommended by the Disability Royal Commission as part of broader recommendations to amend the Intergovernmental Agreement on Nationally Consistent Worker Screening for the National Disability Insurance Scheme.

We acknowledge that an expansion of NDIS worker screening arrangements may require more nuanced approaches to assessing the risk that a worker may pose to people with disability than have been taken to date. We have heard that the application of the risk assessment may be excessively conservative in some cases – with a detrimental impact on entry into the workforce, particularly in regional and remote areas and communities that have a much higher rate of contact with the justice system (including First Nations people).[2298]

While the worker screening process is essential to screen out prospective workers who pose an unacceptable risk to people with disability, the risk assessment should not be used to screen out any worker with a criminal history. An excessively conservative application of the risk assessment can not only contribute to workforce shortages, but may itself also increase risks to people with disability if they are unable to find workers to deliver necessary supports.

> *"Aboriginal communities have long reported the serious barrier to employment posed by employers' use of criminal record checks, irrespective of the relevance of the*

criminal history." – Inclusion Australia's submission to the Australian Government's Employment White Paper [2299]

"The NDIS worker screening check is also a barrier to recruitment for some staff and board members, particularly for regional and remote organisations with a small local recruitment pool. The higher rates of incarceration in Aboriginal people unfairly takes away the opportunity for many Aboriginal people to work in the disability sector." – Aboriginal Health Council of Western Australia [2300]

While worker screening is an effective preventative safeguard, it is not sufficient to guarantee that all workers have the competencies required to deliver safe and quality supports to people with disability. As noted above, responsibility rests with registered providers to ensure all workers have the necessary skills, competencies and qualifications. However, we have heard different views on whether certain qualifications and training should be mandated.[2301] Some argue there is merit in mandatory training to build the capabilities of the workforce. Others express scepticism about the utility of training in driving improvements in the quality of supports, and raise concerns about the challenges of prescribing qualifications and training given the diversity of supports delivered in the NDIS.

We consider that worker screening requirements should be accompanied by mandatory basic online training in working with people with disability and understanding obligations in the NDIS. This could leverage existing e-learning modules designed by the NDIS Commission, such as the 'New Worker NDIS Induction Module' and 'Quality, Safety and You Module'.[2302]

Beyond this, other actions that we are recommending will support efforts to improve the quality, competency and training of workers in the NDIS. This includes designing and trialling a portable training scheme (see Action 15.1), and enhancing capacity-building initiatives to support providers and workers to improve quality (see Action 12.2). As part of these capacity-building initiatives, the new National Disability Supports Quality and Safeguards Commission should be able to draw on the worker screening database to use worker contact details to communicate directly with workers about the availability of resources, training opportunities or guidance.

We also see opportunities to work towards recording and making public information about competencies, qualifications and micro-credentials in the worker screening database, to allow workers to demonstrate their capabilities to providers and consumers. This is consistent with work being progressed in aged care as part of the implementation of a National Aged Care Worker Registration Scheme.[2303] This could also be connected to the Australian Government's consideration of a National Skills Passport.[2304]

3.2.3. Worker screening processes and operations need to be improved, streamlined and harmonised across the care and support sector

NDIS worker screening is intended to be nationally consistent and portable across states and territories.

However, as we discussed in our paper on 'Building a more responsive and supportive workforce' published in May 2023, there are differences in the way these checks have been operationalised across states and territories, and process and timing challenges involved in receiving a check.[2305] Taken together, these arrangements can create delays for employers in sourcing the workers they need, including creating barriers for workers in other sectors to joining the NDIS workforce. Addressing these challenges is particularly important in the context of expanding the coverage of mandatory worker screening (see Action 17.4).

As described in Section 3.2.1, there are multiple steps required to complete worker screening, which can be time consuming for workers and providers:

> **Application:** A worker applies through the relevant state or territory worker screening unit. The worker screening unit verifies the worker's identity and collects a service fee, before the application is sent to the NDIS Commission's National Worker Screening Database.
> **Verification by employer:** The NDIS Commission's National Worker Screening Database emails the applicant's nominated employer to confirm their linkage to the worker.
> **Assessment by worker screening unit:** Once employer verification is complete, the worker screening unit undertakes the assessment process and then clears or excludes the worker.

Each state and territory worker screening unit differs in the time it takes to process a worker screening application. While states and territories are working towards consistent timeframes for processing of worker screening applications, there continues to be significant difference between states and territories in the time taken to process NDIS worker screening applications (Figure 163). There is also limited transparency on the total time taken to progress an application, from the point a worker applies to when they receive either a clearance or exclusion, with reporting on processing times only covering two of the three steps involved.

Figure 163: Median business days for verification (days for an application to be first verified) and assessment (days for an application to progress to clearance or exclusion) by quarter from July 2022 to March 2023[2306]

		ACT	NSW	NT	QLD	SA	TAS	VIC	WA	National
Q1 2022-23	Verification (Step 2)	8	3	11	2	3	6	3	2	3
	Assessment (Step 3)	3	1	3	1	1	5	1	1	1
	Total (Steps 2+3)	11	4	14	3	4	11	4	3	4
Q2 2022-23	Verification (Step 2)	5	3	8	2	5	5	3	2	3
	Assessment (Step 3)	3	1	3	1	2	6	1	1	1
	Total (Steps 2+3)	8	4	11	3	7	11	4	3	4
Q3 2022-23	Verification (Step 2)	7	3	7	2	8	10	2	2	3
	Assessment (Step 3)	3	1	3	1	1	3	1	1	1
	Total (Steps 2+3)	10	4	10	3	9	13	3	3	4

We have only published median worker screening processing times, because two jurisdictions objected to the publication of average worker screening processing times. The median shows the midpoint processing time in the distribution; in other words in one-half of the cases the processing times were less than the median and in the other half processing times were longer. However, if for example, there are a large number of processing times which are very long (or short), the average processing time is also very helpful in presenting a complete picture. For this reason, we believe average, as well as median processing times, should be publicly available to measure performance going forward.

It should be noted that:

- Processing times should be considered with reference to both the time taken for an application to be verified and the time taken for an application to be assessed and progress to clearance or

exclusion, noting such timeframes are impacted by the time taken for an employer to verify a worker's application.

- Application processing times for employer verification are calculated based on the date and time that the application is lodged by an applicant in the state or territory system.

- The data between individual jurisdictions is not directly comparable. Each jurisdiction has different processes and procedures to process applications. For example, the proportion of applications processed manually, which includes time taken to verify an applicant's identity, will affect the processing time and some jurisdictions may have a higher level of manual processing than others.

Further, while intended to be nationally consistent, there are differences in the operationalisation of these checks between states and territories. Some jurisdictions do not allow workers to commence work until they have received a clearance, and most jurisdictions require workers to receive other state-based clearances (for example, requiring a Working with Children Check as well as an NDIS Worker Screening Check when delivering NDIS supports to a child). Some jurisdictions also rely on manual processes (for example, requiring individuals to verify their identity in person).[2307] Together, these differences can also add to the variation in times for processing worker screening applications and delays for workers commencing work.

As recommended in our May 2023 paper on 'Building a more responsive and supportive workforce', NDIS worker screening should be improved and streamlined, including through efforts to improve processing times and transparency.[2308] We also want to see greater harmonisation and mutual recognition of checks across the care and support sector, to support workers operating across different parts of the wider sector.

3.2.4. Action & Implementation Details

Action 17.4: The Department of Social Services, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should expand the coverage of worker screening requirements

Worker screening should be mandatory for all individuals working in risk assessed roles for registered providers, and all individuals working for enrolled providers in roles where normal duties include the direct delivery of specified supports or services to people with disability or are likely to require more than incidental contact with people with disability. Expanding worker screening requirements to these roles would support a more risk-proportionate approach to regulation, ensuring workers do not pose an unacceptable risk to people with disability. Expanded worker screening requirements should be informed by engagement with people with disability, providers, workers and unions and adopted as part of the new regulatory model (see Action 17.1). This should be accompanied by mandatory basic online training for workers to understand their obligations.

Implementation detail:

- The Department of Social Services, the new National Disability Supports Quality and Safeguards Commission and state and territory governments should expand worker screening requirements, and consider the following related features and actions:

  - Worker screening requirements should apply to all relevant individuals working for providers regulated by the new National Disability Supports Quality and Safeguards Commission, whether they are providing NDIS supports or other Australian Government funded disability and foundational supports.

  - The expansion of worker screening requirements should be staged as part of transition arrangements for the new graduated and risk-proportionate model (see Action 17.2).

  - Worker screening requirements should be accompanied by mandatory basic online training on working with people with disability and understanding obligations in the NDIS. This training could leverage existing e-learning modules designed by the NDIS Commission, such as the 'New Worker NDIS Induction Module' and 'Quality, Safety and You Module'.

  - Further work should be undertaken to allow the worker screening database to record and make public additional information about workers, such as qualifications, micro-credentials and competencies. Action 15.1 details further work to design and trial workforce attraction initiatives, including trialling a portable training scheme.

  - The new National Disability Supports Quality and Safeguards Commission should draw on the worker screening database and record of worker contact details to communicate information resources, training opportunities and guidance directly to workers.

  - Efforts must be made to ensure the application of screening to a much larger number of workers does not inappropriately impact workforce availability or impose excessive costs and burdens. This should include:

    o Improving administrative processes and harmonising requirements and processes across jurisdictions and with other similar checks (see Action 17.5).
    o Applying a nuanced and risk-based approach to assessing the risk of workers, to ensure that workers are not inappropriately excluded and that there is consistency in decision-making across states and territories.
    o Applying a nuanced and risk-based approach to specifying supports and services for which direct delivery requires worker screening under Section 7 of the *National Disability Insurance Scheme (Practice Standards – Worker Screening) Rules 2018*, so as not to unreasonably apply the requirement for worker screening.

  - Opportunities should be explored to identify and utilise broader inputs of intelligence to ensure worker screening is using all available intelligence about potential risk. This

includes identifying new sources of information may be useful in assessing the risk an individual may pose to people with disability, and exploring further opportunities to share information with other agencies and use regulatory intelligence gathered by other regulators in the care and support sector.

📑 Action 17.5: The Department of Finance and the Department of Social Services, working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should improve, streamline and harmonise worker screening processes for care and support workers

Expanding worker screening requirements to more NDIS workers (see Action 17.4) should be supported by efforts to improve the operation of the worker screening process. This should include urgent work to reduce timeframes, improve consistency across jurisdictions and streamline and harmonise checks across the care and support sector.

Implementation detail:

- The Department of Finance (through the Regulatory Reform Division) and the Department of Social Services (DSS), working with the new National Disability Supports Quality and Safeguards Commission and state and territory agencies, should ensure the current processes for the NDIS Worker Screening Check is improved and streamlined without reducing the level of safeguards offered under the NDIS by:

  - Reducing worker screening processing times by removing the requirement that an application for employees needs to be verified by an employer (providers can link to workers after the clearance is complete).

  - Considering expanding work on application provisions to all jurisdictions with appropriate and aligned risk mitigation measures.

  - Exploring if NDIS Worker Screening Checks could be recognised as fulfilling the requirement for Working with Children Checks (WWCC) and Police Checks across all jurisdictions.

  - Improving the efficiency and quality of checks by minimising reliance on manual processes. This should include looking at opportunities to improve data sharing, systems design, IT requirements and draw on existing established identification systems (such as, but not limited to, myGovID).

  - Providing greater ongoing transparency on end-to-end clearance times, with improved data quality to ensure comparability between jurisdictions.

- The Department of Finance, working with state and territory governments, as well as DSS and the new National Disability Supports Quality and Safeguards Commission, should also ensure the aged care worker screening requirements being developed as part of the National Aged Care Worker Registration Scheme align with the NDIS Worker Screening Check, and that checks are mutually recognised across programs.

3.3. Regulatory settings have not responded to reflect changes in the market, clarify expectations on long-standing and emerging quality and safeguards issues, or support innovation

Regulatory settings have not been updated to effectively respond to a range of long-standing and emerging quality and safeguards issues or changes in the market, such as the introduction of new supports. This has caused uncertainty in the market around how to comply with requirements or manage certain issues as they arise, with impacts on the safety and quality of supports that participants receive.

A much more proactive regulatory posture is required. The new National Disability Supports Quality and Safeguards Commission must ensure it responds to issues that emerge by using the full range of its broad regulatory powers and levers (for example, providing guidance, setting new standards and taking compliance action where appropriate), while also taking a more open approach to support innovation in the interests of consumers.

3.3.1. Long-standing and emerging quality and safeguards issues have not been appropriately addressed in regulatory activities, and clear expectations have not been set for providers and workers

We note that the NDIS Commission has developed guidance for providers on some systemic risks in support delivery, including guidance around mealtime management, severe dysphagia, and emergency and disaster management.[2309] These guidance products are informed by research and designed to respond to issues that emerge in support delivery and the NDIS Commission's monitoring of the market.

However, we have also heard through submissions and other engagement that there are a number of long-standing and emerging issues that would benefit from the new National Disability Supports Quality and Safeguards Commission strengthening its activities with a sense of urgency, including through providing information and guidance as well as taking an assertive compliance posture where required. In particular, we have heard feedback from providers, people with disability, families and carers on issues related to conflicts of interest and client capture, sharp practices (including service agreements), transparency and duty of care.

Conflicts of interest

Conflicts of interest can occur where "someone has real or perceived competing private and professional interests. These interests may make it difficult to fulfil their professional duties without bias or the perception of bias".[2310]

In the NDIS, a conflict of interest may occur when the same provider or related providers are delivering all or most supports to a participant, or where a provider is delivering support for decision-making and may bias the participant to choose supports from the same provider, instead of recommending supports from other providers that are more appropriate.[2311] While the NDIA has provided some guidance to support coordinators, there continue to be concerns about conflicts of interest, such as situations where a single provider or related providers deliver supported independent living supports and Speciality Disability Accommodation.[2312]

> *"...it is unconscionable that a provider can provide plan management and support coordination services to the same participant. Similarly, support coordination and therapeutic supports. I have even seen equipment suppliers also providing therapeutic supports." – Provider[2313]*

The NDIS Practice Standards already seek to address conflicts of interest generally in the standards that apply to all registered providers, as well as certain specialist standards for particular supports (specifically, Specialist Support Coordination and Specialist Disability Accommodation). This includes expecting that providers effectively and proactively manage these conflicts, that conflicts are appropriately documented, and that participants are informed. However, more should be done to improve guidance for all providers and participants on conflicts of interest, coupled with a stronger focus on compliance activities. We are also making a specific recommendation to mandate separation between Specialist Disability Accommodation providers and providers of home and living supports (see Chapter 3 and Action 9.7).

Client capture

A particular concern associated with conflicts of interest is client capture – where providers or workers may unduly influence and exploit participant decision-making, particularly in situations where the provider delivers all or most supports to a participant.

The recommended introduction of Navigators and better and more timely data on participant expenditures will assist in identifying these situations. However, these situations can be very complex and so further engagement is required with disability and advocacy representative organisations and provider representatives to develop mechanisms to identify and respond to client capture.

Sharp practices

Sharp practices include dishonest or barely honest behaviours that are not necessarily unlawful but are unethical, unscrupulous or not in the interest of people with disability, and involve unfair treatment or taking advantage of people.[2314]

We note that the NDIS Commission, the Australian Competition and Consumer Commission and the NDIA have reminded providers of their obligations to treat consumers fairly.[2315] However, we have continued to hear a range of concerns about sharp practices, and in particular about service agreements that appear to be excessive and inaccessible and include unreasonable or unfair terms of service, and of providers not appropriately engaging participants or their supporters in the development of service agreements.[2316] There is limited guidance for either providers or participants around service agreements or sharp practices more broadly, and an insufficiently assertive posture to taking compliance action in response to such issues.

> *"...we are aware that NDIS participants find that service agreements are too complex, jargon-heavy, overly long, unclear, and include punitive cancellation terms and other unfair terms. Power imbalances are an important consideration and NDIS participants are often disempowered relative to businesses and service providers when it comes to negotiating and agreeing to terms of service." – Consumer Action Law Centre[2317]*

> *"I have concerns that NDIS Providers are not engaging appropriate supports - such as Public Guardians as they are not understanding or reinforcing the participants human rights. There are providers who are making all decisions for a participant as they do not want to engage any third party supports, these providers are also signing legal documents on behalf of the participant." – Person with disability[2318]*

We believe service agreements should be written in a way that a person with disability can understand and should generally not include complex terms of service or legal jargon, which are inaccessible to some people with disability.[2319] We have also heard some suggestions that there would be value in model or standard terms for service agreements.[2320] The new National Disability Supports Quality and Safeguards Commission should provide more guidance and support to ensure service agreements are appropriate. This should include working with people with disability and their supporters, as well as the Australian Competition and Consumer Commission, state and territory consumer protection agencies, and Public Guardians and Public Advocates to develop clear actions to address issues around service agreements. This is consistent with the recommendations for action outlined by the Victorian Office of the Public Advocate in 2019, which identified issues we have also heard in this review.[2321]

Openness, honesty and transparency

We have also heard that people with disability, their families and carers want to see more openness, honesty and transparency when things go wrong, from both providers and the NDIS Commission.

> *'When a person makes a complaint, they feel they have already been wronged... While an expected outcome will differ in every case, some examples from our experience include: An apology... [or] an honest and transparent account of why the problem occurred, and a credible explanation as to how it will be prevented from happening again... [or] an explanation as to why the service provider did not take this issue seriously in the first place, and how future complaints will be handled more*

appropriately... [or] Repercussions for service providers who have caused harm. This could be as simple as the Commission explaining that the service provider has been asked to take certain actions, and should a further complaint occur which demonstrates that they didn't, the Commission would do something more substantive.'
– Villamanta Disability Rights Legal Service [2322]

While the NDIS Code of Conduct directs providers and workers to act with integrity, honesty and transparency, a stronger culture of transparency and open disclosure amongst providers would support people with disability. This will require more explicit articulations of expectations and examples for providers of what this looks like in practice.

Consideration should be given to other frameworks that effectively model openness, honesty and transparency in health and social services, including the Australian Open Disclosure Framework,[2323] designed to support health service organisations and clinicians to communicate openly with patients when health care does not go to plan. Consideration should also be given to a similar concept embedded in England's health and social services system, where a statutory Duty of Candour requires health and social services providers to be open and transparent with people receiving their services.[2324]

It is important that this openness and transparency is modelled by the new National Disability Supports Quality and Safeguards Commission to set the standard for the market, including through much improved communication with people who raise issues to support them to understand how their issue has been considered and addressed. A major complaint about the NDIS Commission is that people lodge complaints but never hear anything back.[2325]

An open and transparent regulator, which follows up in a timely manner, would build more confidence, send clear signals to the market about accountability to people with disability for the supports they provide, and better support the active involvement of people with disability in the resolution of issues. The new National Disability Supports Quality and Safeguards Commission cannot expect providers to adopt an open and transparent approach without leading and showing the way.

Duties of care

We have also heard feedback seeking clarity on duties of care that arise in the provision of NDIS supports. A duty of care is a legal obligation to avoid one's actions causing harm to others, and arises where harm is reasonably foreseeable if care is not taken. We have heard calls for a statutory duty of care to be enshrined in NDIS legislation, consistent with developments in aged care regulation following a recommendation of the Royal Commission into Aged Care Quality and Safety.[2326]

However, we consider that NDIS providers and workers already have enforceable duties of care for participants conferred on them under common law and work health and safety law, and enforceable duty of care-like obligations conferred on them by the NDIS Code of Conduct and NDIS Practice Standards. For example, the NDIS Code of Conduct, which applies to all providers and workers, specifically directs providers and workers to deliver supports and services in a safe

and competent manner, with care and skill,[2327] and is consistent with the duty of care concepts in both common law and work health and safety law. Expectations of duties of care are likely to look different for different types of supports – for example, differences between the expectations of a provider of 24/7 living supports with significant contact with a participant, versus an allied health practitioner with less frequent and more limited contact with a participant.

We have observed there to be a lack of awareness across the system of these key protections, how they apply, and how participants and their supporters can seek action under them in response to breaches by providers and workers. There are also opportunities to more assertively enforce these obligations.

> *"Ambiguously defined duties [regarding duty of care] increases the risk of 'buck passing' around safeguarding, where the Commission identifies adverse care outcomes for which no party assumes responsibility." – Health Services Union (National)[2328]*

We believe the most effective response to these issues will be improved guidance and education for providers, workers and people with disability to clarify rights, obligations and expectations – supported by the new National Disability Supports Quality and Safeguards Commission taking a more assertive approach in pursuing enforcement action in response to related breaches of provider and worker obligations.

The response to these issues will also be supported by the recommended risk assessment and safeguard building process (see Action 16.2), which will support the identification of, and response to, particular risks (such as where a participant might be at greater risk of capture, coercion or sharp practices by a provider). Similarly, the implementation of a range of personalised developmental safeguards (see Action 16.3) will build the capacity and natural safeguards of participants, better enabling such issues to be raised.

3.3.2. The regulatory posture is too reactive and must be more proactive in responding to change in order to encourage innovation

There has been limited guidance and information developed for new supports and models of support delivery as they emerge. This means that current regulatory settings are often not reflective of, or responsive to, new and innovative supports being introduced into the market – including by establishing clear outcomes and expectations for the delivery of these supports. For example, the introduction of platform providers, and the way in which they engage workers on their platforms, may create different regulatory obligations, compared to more traditional organisations. However, there has been limited guidance and information provided about these issues.

Changes to regulatory settings appear to mostly occur retrospectively and in response to issues and risks having materialised. This includes through learnings and insights from the NDIS Commission's Own Motion Inquiries into supported accommodation, platform providers and most recently on support coordination and plan-management,[2329] as well as through the collection of regulatory intelligence (for example, complaints and reportable incidents). However, this is

predominantly a reactive approach to updating regulatory settings, and is typically more focused on responding to harm rather than proactively engaging with change and innovation that will benefit consumers.

Going forward, the new National Disability Supports Quality and Safeguards Commission should proactively engage with innovative providers, for example through trialling collaborative models to observe and consider the regulatory approach for innovative support types or delivery models. This is often referred to as a 'regulatory sandbox' approach.

Regulatory sandboxes provide opportunities for a regulator to engage with providers and support the testing and observation of innovative support types or delivery models.[2330] This assists regulators in determining how an innovative support should be regulated (for example, determining the standards that should apply and the way in which a support could demonstrate compliance). Regulatory sandboxes have largely been used in other sectors, such as energy and financial services. However, research and best practice has suggested further use of regulatory sandboxes in other sectors, such as healthcare,[2331] and some human services regulators have begun testing regulatory sandbox models (Box 93).

Box 93: Care Quality Commission's Pilot of a Regulatory Sandbox[2332]

The Care Quality Commission in England recently completed and evaluated a pilot of a regulatory sandbox, working collaboratively with innovative providers, people with lived experience, and other regulators to understand how technological innovation is being used in support delivery and how innovative services should be regulated.

The pilot considered the use of machine learning in screening and diagnostic tools and digital 'triage' tools (software that tells a person where to go next in a care pathway or process). Another pilot considered the use of paid personal assistance delivered by micro-providers supported by digital umbrella agencies (somewhat comparable to sole traders operating on platforms), but was put on hold due to COVID-19 and therefore not included in the evaluation.

The Care Quality Commission found that the regulatory sandbox was effective in considering regulatory challenges quickly and efficiently, and improved the reputation of the regulator by building a perception of it as more open to innovation.

There is benefit in the new National Disability Supports Quality and Safeguards Commission considering such approaches to support innovation in NDIS markets that will ultimately deliver greater choice and other benefits to people with disability. This approach would allow clear avenues to test and trial innovative models with appropriate regulatory oversight, and provide insights into how regulatory settings may need to be adapted to support beneficial innovation.

3.3.3. Action & Implementation Details

Action 17.6: The new National Disability Supports Quality and Safeguards Commission should be resourced to strengthen compliance activities and communications to respond to emerging and longstanding quality and safeguards issues, and market developments and innovation

Immediate priorities should include improving communication of expectations and good practices for providers, as well as strengthening compliance activities, relating to conflicts of interest and client capture, sharp practices and service agreements, transparency and open disclosure, and duties of care. On an ongoing basis, a more proactive approach should be taken to ensure innovation and change in the market is appropriately considered and incorporated into regulatory settings, including to support beneficial innovation. This should include trialling collaborative models to observe and consider the regulatory approach for innovative support types or delivery models.

Implementation detail:

- The new National Disability Supports Quality and Safeguards Commission should immediately strengthen information and guidance for people with disability and providers, and take a more assertive enforcement posture where required, on the following issues:

  - Conflicts of interest and client capture: Regulatory requirements, guidance and compliance activities should be strengthened to respond to situations where the same provider (or related providers) deliver all or most supports to an individual. Further engagement should also be undertaken with disability and advocacy representative organisations and provider representatives to develop mechanisms to identify and respond to client capture.

  - Sharp practices: Further guidance and information should be developed to clarify expectations for providers regarding sharp practices (that is, practices that are dishonest and unethical, but that may not pose immediate safety concerns). Information should also be provide to support people to identify and raise concerns around such practices. As part of this:

    o The new National Disability Supports Quality and Safeguards Commission should regularly consult with the NDIA, the Independent Health and Aged Care Pricing Authority and other regulators in adjacent markets about sharp practices, as part of its market monitoring role and in order to ensure a comprehensive and coordinated approach to these issues.

    o The new National Disability Supports Quality and Safeguards Commission should develop an action plan to respond to specific issues regarding service agreements that are unfair or place inappropriate pressure on people with disability. This should include applying a more assertive enforcement posture,

providing clear information to people with disability and their supporters on how and where to raise concerns about service agreements, and providing clear information for providers about what an appropriate service agreement should include (for example, by developing and publishing example agreements). This should include working with the Australian Competition and Consumer Commission, state and territory consumer protection agencies, and Public Guardians and Public Advocates to inform clear actions to address issues regarding service agreements.

- Transparency and open disclosure: The new National Disability Supports Quality and Safeguards Commission should set the example for the market and establish a culture of open disclosure, setting expectations for transparency from providers to people with disability, their families and carers regarding incidents that have or may impact on the safety, health and wellbeing of people with disability.

  o In doing so, consideration should be given to the principles expressed in the open disclosure framework administered by the Australian Commission on Safety and Quality and Health Care and the 'duty of candour' regulated by the Care Quality Commission in England.

- The new National Disability Supports Quality and Safeguards Commission should also immediately strengthen guidance regarding duties of care conferred on providers, and take a more assertive posture in enforcing breaches of these obligations. This should include:

  - Strengthening guidance regarding the existing duties of care conferred on providers through common law and work health and safety law, and the duty of care-like concepts in the Code of Conduct and Practice Standards, including to highlight rights enshrined in the UN Convention on the Rights of Persons with Disabilities.

  - This should involve providing information to people with disability and their supporters on how duties of care are applicable to the services they use. It should also involve providing guidance and information for providers, their responsible and/or governing persons and workers to make clear their existing duties of care and duty of care-like obligations, how they interact, and what penalties they face if they breach them.

  - Taking a more assertive enforcement posture to take action on breaches of existing obligations and duties of care, including working with state and territory work health and safety regulators.

  - Monitoring (with the Department of Social Services) the development of a statutory duty in aged care, with view to considering a similar duty in the NDIS context if successful.

- The new National Disability Supports Quality and Safeguards Commission should better identify changes or innovation in the market, and update regulatory settings on an ongoing basis if required to respond to and incorporate new supports or models of support delivery. In doing so, the new National Disability Supports Quality and Safeguards Commission should consider trialling collaborative models (referred to as 'regulatory sandbox' models) to engage with providers and support the testing and observation of innovative new supports which may not clearly fit into existing regulatory settings.

  - Following this, regulatory settings could be updated or adapted to respond to and enable beneficial innovation (for example, through adjustments to standards and compliance requirements, or through guidance and information for the market).

4. Continuous quality improvement

- Safe supports are essential for all people with disability. However, they must be accompanied by a renewed and sharper focus on improving quality. Quality in this context can be defined as the extent to which supports meet or exceed a person's needs and expectations, and goes beyond minimum safety requirements. Together, an integrated approach to quality and safety is key to people with disability achieving good outcomes, preventing harm and ensuring safeguarding.

- To date, regulatory effort has been focused on transitioning disparate state and territory arrangements to a national approach. Alongside resourcing constraints in the NDIS Quality and Safeguards Commission (NDIS Commission), this has resulted in limited focus on efforts to drive continuous quality improvement.

- Similarly, many providers have primarily directed their focus to regulatory compliance rather than quality improvement, with limited understanding about what good quality looks like or how to implement quality improvements in their support delivery and operations. Some providers also feel that current pricing and payments arrangements constrain their ability to invest in quality improvements.

- Auditing is a key regulatory process intended to encourage quality support delivery. However, it is too focused on the procedures and policies of providers, rather than the quality of support delivery and the voices and experiences of people with disability as consumers. This further undermines the value of registration, with both providers and participants perceiving that regulation is not genuinely adding to the quality of support delivery.

- There are also few incentives in the NDIS for providers to improve – and compete on – the quality of the supports they deliver. This results from limited information available about the quality of supports and providers to show providers how they are performing and empower people with disability and their supporters to be active and informed consumers.

- There is no one silver bullet to improve quality, and instead a range of reforms are required. The right foundations must be established by ensuring quality inputs through capacity-building, guidance and outreach that supports providers and workers to understand and deliver good quality supports; auditing that elevates the focus on quality; auditing processes and Navigators that amplify the voices of people with disability in improving service quality; and pricing and payments approaches that enable and encourage the provision of quality supports (see Chapter 4). On top of these foundations, measuring and publishing information about provider performance will incentivise providers to engage in and compete on quality improvement, and support people with disability and their supporters to be more active and informed consumers.
- These reforms should be supported by a much stronger focus on quality in the new National Disability Supports Quality and Safeguards Commission, led by a dedicated Deputy Commissioner for Quality. It should give immediate priority to lifting quality across key areas we have identified throughout this Review, including behaviour support, navigation, early intervention, psychosocial supports, housing and living supports, and supports for children, families and First Nations people.

Recommendation 12: Embed, promote and incentivise continuous quality improvement in the market, supported by a dedicated quality function in the new National Disability Supports Quality and Safeguards Commission

🗐 Legislative change required

- Action 12.1: The Australian Government should establish and appropriately resource a quality function within the new National Disability Supports Quality and Safeguards Commission led by a dedicated Deputy Commissioner for Quality.
- 🗐 Action 12.2: The new National Disability Supports Quality and Safeguards Commission should make quality improvement a priority in capacity-building initiatives and audit processes.
- 🗐 Action 12.3: The new National Disability Supports Quality and Safeguards Commission, working with the Department of Social Services, should design, test and implement an approach to measure and publish metrics of registered provider performance.

4.1. There has been insufficient focus on continuous quality improvement by both the regulator and many providers

With constrained resources, the NDIS Commission's regulatory effort, initiatives and processes have been primarily directed toward transitioning to nationally consistent safety standards, with comparatively limited attention given to lifting quality. This has raised questions about whether responsibility for driving quality in the market should remain with the NDIS Commission or be moved to another agency. Research and best practice tells us that quality and safety are interconnected, with safety being a dimension of quality.

To address these concerns, the new National Disability Supports Quality and Safeguards Commission should include a dedicated and appropriately resourced quality function, led by a Deputy Commissioner for Quality, to lead initiatives to drive continuous quality improvement in the market and embed a focus on quality across all regulatory activities.

4.1.1. The regulator and providers have rightfully prioritised setting, enforcing and complying with safety standards, however this has been at the expense of efforts to improve quality

As NDIS quality and safeguarding arrangements have been rolled out (with the full transition to national regulatory arrangements having only concluded in July 2023), the NDIS Commission has directed its regulatory effort towards establishing and operating its regulatory functions and processes, focusing predominantly on nationally consistent safety standards and with limited efforts to improve quality.

This was an appropriate choice for the NDIS Commission to make, in the context of the significant volume of work involved in transitioning disparate state and territory arrangements to a national regulatory approach, combined with the significant resourcing constraints it faced.

More recently, the NDIS Commission has begun to implement a number of positive quality improvement initiatives (see Section 4.2.1 for examples). However, a more focused and targeted approach to driving quality is required.

Similarly, to date most providers have tended to focus on ensuring compliance with standards and requirements, rather than engaging and investing in innovation and quality improvement.

> *"Massive under-investment in assistive technology, innovative new care models and big data analysis means the scheme is not evolving as quickly as it could. This results in a massive misallocation of resources, poorer participant outcomes, significantly higher levels of inefficiency and waste, artificial competition for resources and extensive corruption." – SDA Plus[2333]*

Compounding this lack of focus by providers, we have also heard some providers report that the current price caps do not sufficiently account for the costs associated with delivering quality supports. We have discussed the importance of pricing and payment approaches as an enabler for the provision of quality supports and our recommended reforms to NDIS pricing and payment approaches to improve incentives for providers to deliver quality supports for participants (see Chapter 4 and Recommendation 11).

> *"...to drive improvements in the quality of supports and services, therapeutic supports need to be priced adequately. High-quality best practice tailored supports delivered by experienced practitioners have a cost and this needs to be recognised through pricing." – Australian Physiotherapy Association[2334]*

4.1.2. Better regulatory focus on improving the quality of supports is needed, supported by an appropriately resourced function

Due to the limited focus on quality to date, we have heard questions around whether responsibility for driving quality improvement in the market should remain with the NDIS Commission or be moved to another agency. We believe that promoting quality is an essential part of provider regulation and is best driven in an integrated approach, alongside safeguarding, by the new National Disability Supports Quality and Safeguards Commission.

Quality can be defined as the extent to which supports meet or exceed a person's needs and expectations. Quality may look different for different people, but key aspects of quality typically include the satisfaction of consumers, the efficacy of support delivery and outcomes achieved, as well as a provider's responsiveness in addressing issues.[2335] A safe support is the bedrock of a quality support. However, quality support goes far beyond safety. Quality support is key to both good outcomes for people with disability, but also importantly to preventing harm and ensuring the safeguarding of people with disability. This is why we believe quality is best driven by an integrated approach with safeguarding.

This is supported by literature on best practice regulation and the approach taken in similar human services regulation – for example, the Aged Care Quality and Safety Commission in Australia and the Care Quality Commission in England.[2336] Integration of these activities also allows regulatory tools and relationships to be leveraged to drive quality improvements.

> *"Safety can be considered one of multiple domains of quality, and safety can also be considered synonymous with quality. Regardless, both safety and quality are driven by systems of care, and improvement methods should focus on understanding and improving these systems." – Gupta, Soll and Suresh (2019)[2337]*

> *"…the focus needs to be on quality and outcomes, rather than simply price. Measuring, reporting and enforcement is the job of the NDIS Commission, not the market. Quality should be the bottom line for eligibility to provide services." – The Australian, New Zealand and Asian Creative Arts Therapies Association[2338]*

Despite this best practice approach, we have observed that efforts to improve quality have tended to take second place to safety in the NDIS Commission's focus. To address this, there must be a strong and sustained focus on driving continuous quality improvement in the market within the new National Disability Supports Quality and Safeguards Commission. This should be achieved by elevating the focus on quality through a dedicated and appropriately resourced quality function, led by a new Deputy Commissioner for Quality.

We note that the NDIS Commission's recent restructure established the position of Deputy Commissioner for Practice Quality and Clinical Advisory (previously the Senior Practitioner position).[2339] However, this role and supporting function is focused on behaviour support and restrictive practices. A Deputy Commissioner for Quality should bring a broader focus on all aspects of quality across the market.

The new Deputy Commissioner for Quality and supporting quality function should have responsibility for quality initiatives, such as commissioning research and developing guidance on best practice support design, undertaking outreach to providers, delivering other capacity-building initiatives for providers and workers, and measuring provider performance. The function should also provide leadership across the organisation to embed and strengthen the focus on quality in other regulatory functions, including improving the audit process to have a stronger focus on quality.

In particular, priority should be given to establishing an appropriately resourced capacity for outreach to providers. This function should facilitate and inform efforts to drive quality in the market by providing opportunities to advise providers on quality improvement, gather intelligence about good practice and innovation in support design and delivery, and identify priority areas for capacity-building initiatives.

Establishing this function as an early priority is also an important enabler for other recommendations we are making – for example, using provider outreach activities to complement, supplement or replace auditing (see Action 17.1), and to take a more proactive approach to gather regulatory intelligence and identify quality and safety issues to inform a more active compliance posture (see Action 19.3).

Reflecting priorities identified throughout this Review, the new Deputy Commissioner for Quality and supporting function should direct immediate priority to efforts to drive quality in relation to behaviour support, navigation, early intervention, psychosocial supports, housing and living supports, and supports for children, families and First Nations people.

The Deputy Commissioner for Quality's activities should also interact closely with other recommendations of this Review, including more targeted research to understand culturally and racially diverse concepts of disability and care (see Action 2.2), the new NDIS Evidence Committee (see Action 23.2) and the new Disability Research and Evaluation Fund (see Action 23.3).

4.1.3.   Action & Implementation Details

Action 12.1: The Australian Government should establish and appropriately resource a quality function within the new National Disability Supports Quality and Safeguards Commission led by a dedicated Deputy Commissioner for Quality

This function should be adequately resourced to deliver on quality improvements. It should drive a range of initiatives to promote quality improvement through capacity-building, improved auditing and greater transparency (see Actions 12.2 and 12.3), and should provide leadership and coordination across the new National Disability Supports Quality and Safeguards Commission to deliver a focus on driving quality improvement in the market.

Implementation detail:

- The new National Disability Supports Quality and Safeguards Commission should establish this function with the following responsibilities:

  - Providing leadership across the organisation on embedding a focus on quality in all regulatory processes and activities.

  - Incorporating an appropriately resourced capacity for outreach to providers to advise on quality improvement; gather intelligence about innovation in support design and delivery; identify requirements for capacity-building initiatives; and monitor performance and compliance.

  - Contributing to, and promoting, research and guidance through the creation of an online 'Centre of Excellence' resource library (see Action 12.2).

  - Developing and implementing other capacity-building initiatives (see Action 12.2).

  - Contributing to the design, implementation, measurement and publication of provider performance against quality and safety metrics (see Action 12.3).

  - Working with other regulators and professional registration bodies to embed a disability focus in other regulatory and professional development requirements, to build quality and capability in working with people with disability in cross-sector providers. For example, this could include working with the Australian Health Practitioner Regulatory Agency (AHPRA) to develop training on working with people with disability as part of continuing professional development requirements for AHPRA professions.

- The Deputy Commissioner for Quality and the new quality function should direct immediate focus to:

  - Developing better strategies to improve the quality of behaviour support plans and drive the reduction and elimination of restrictive practices (see Recommendation 18).

  - Establishing quality expectations and outcomes for Navigators (see Recommendation 4). This should also include designing tools and guidance to support people with disability and Navigators to identify and manage quality supports.

  - Contributing to research and evidence on good quality and promoting good practice through guidance for all early intervention supports (see Recommendation 6). This should include a particular focus on ways to drive quality in the delivery of these supports for children, as well as supporting families, Navigators and Lead Practitioners with advice on good practice and effective early intervention strategies. This will require close collaboration with the National Disability Insurance Agency (NDIA, which will be commissioning Navigators and Lead Practitioners), as well as working with the NDIS Evidence Committee (see Action 23.2).

  - Delivering strategies, initiatives and guidance on good practice to drive quality in providers delivering psychosocial disability specific supports (see Recommendation 7).

- Developing approaches that embed culturally safe practices and better support the intersectional identities of people with disability, such as First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities (with a priority focus on First Nations linked to whole-of-sector First Nations capability uplift and the First Nations Disability Commissioner – see Action 2.10), culturally and linguistically diverse communities, and sexuality and gender diverse people. This may include amendments to Practice Standards to better connect quality with intersectional needs for people with disability and culturally diverse concepts of disability and care (see Action 2.2); promoting models of support that work best for communities; and workforce capability initiatives such as intersectional training alongside community representative bodies (see Action 20.4).

- Translating knowledge and promoting good practice and innovative delivery models for housing and living supports. This could include the translation of learnings from the implementation of innovative accommodation models (for example, co-located housing that offers individual privacy while facilitating best-practice sharing of supports); household governance approaches (for example, family governance models); and approaches to the delivery of living supports (for example, Active Support and Frontline Practice Leadership – see Chapter 3). These efforts should occur alongside Navigations, who will also play a key role in knowledge translation (see Chapter 3).

- Building the capacity and quality of independent decision-supporters, and promoting best practice and quality support for decision-making for both independent decision supporters and support workers (see Recommendation 5).

4.2. There has been insufficient support for providers and workers to engage in quality improvement, and key regulatory processes have lacked a focus on the quality of supports and the voices of people with disability

The quality of providers and supports varies greatly across the NDIS, with only some providers focused on, and investing in, continuous quality improvement. This is driven by a number of factors, including a lack of understanding about what good quality support delivery looks like, and insufficient embedding of a focus on quality in regulatory processes.

While some capacity-building approaches have been implemented to support quality improvement, more focused efforts are required to ensure providers understand what good quality looks like. This should be done alongside improved and refocused auditing that supports improvements in quality and elevates the voices and perspectives of people with disability. Together, this will ensure that providers and workers understand what good quality looks like and how to implement this in their delivery of supports.

4.2.1. More effective and targeted capacity-building initiatives are required to support providers and workers to engage in continuous quality improvement

More recently, the NDIS Commission has begun to implement a number of positive quality improvement initiatives, including the NDIS Workforce Capability Framework, which describes the attitudes, skills and knowledge expected of all workers in the NDIS; an online repository of resources called 'Evidence Matters' dedicated to developing quality behaviour support plans and reducing restrictive practices; and practice alerts on best practice support delivery (for example, for oral health and pain management).[2340]

However, we have heard from many providers and workers who feel there is still not enough targeted and focused information, training and resources to help them understand what good quality support delivery looks like and how they can implement this in practice.

> *"[C]apability building is more than just a website article but instead requires training, education among the sector and building information awareness through a proactive means" – The CEO Collaboration[2341]*

> *"Beyond these self-service learning options, the Commission has demonstrated minimal commitment to the training and education of service providers under the current Framework." – Vision Australia[2342]*

In particular, we have heard feedback about the importance of building the capability of the workforce. The Workforce Capability Framework is a useful resource that provides practical guidance on the attitudes, skills and knowledge expected of all NDIS workers, however it does not set requirements for learning and improvement.[2343]

We believe that more can be done to build the capability of the workforce, including through trialling a portable training scheme for the care and support sector (see Action 15.1) and requiring basic online training as part of NDIS worker screening (see Action 17.4). In addition to this, further initiatives to build the capability of the NDIS workforce should be driven by the Deputy Commissioner for Quality (see Action 12.1) through more targeted and focused capacity-building initiatives for workers, including by leveraging and building on the Workforce Capability Framework.

> *"The NDIS Act's objectives entail more ambitious goals for workforce development and quality standards driven by innovation and continuous improvement beyond ensuring a worker is capable of delivering support work." – Health Services Union (National)[2344]*

We have heard that more active engagement with industry bodies is required to identify and disseminate best practice, information resources and training opportunities.

> *"A greater commitment by the Commission to meaningful engagement and dialogue with service providers should be considered as a key component of this review." – Vision Australia[2345]*

The new National Disability Supports Quality and Safeguards Commission should better involve industry partners in efforts to drive quality in the market by taking a partnership approach and establishing forums to communicate expectations to the market. This should be supported by greater outreach to providers, including in partnership with industry bodies, and more place-based initiatives, including building on recent campaigns in Cairns and Launceston that were well received.[2346]

We have also heard strong feedback from providers about a desire for the NDIS Commission to share more data and insights, drawing on the data and regulatory intelligence it collects from providers.

> *"Greater use, interrogation and interpretation of data (including more publicly available information regarding aggregated audit findings)... [This] could allow for deep and authoritative insights into the state of quality and safeguarding across the country." – National Disability Services[2347]*

Providers have emphasised that the sharing of insights from data about what is working well and where change is needed would support their efforts to improve quality. This was also raised by the Disability Royal Commission, which noted that many providers want to use transparent benchmarked data about reportable incidents and complaints, results of audits, and details of compliance action taken in the market to reflect on and improve the quality of their support delivery.[2348]

4.2.2. Audits are focusing too much on policies and procedures, rather than embedding quality improvement and elevating the voices of people with disability

As outlined in Section 3.1, registered providers are required to undergo an external third party quality audit to demonstrate compliance with relevant NDIS Practice Standards and associated Quality Indicators. Audits assess evidence of a provider's compliance with relevant NDIS Practice Standards in a variety of ways, including through observation and desktop assessments, and capturing the experience and feedback of participants.[2349] This provides opportunities to support quality improvement by providers.

However, we have heard through submissions and previous inquiries that auditing is not working as intended to assess and promote quality support delivery. We have heard that audit quality is variable, and that audits are often too focused on paperwork, procedures and policies and not focused enough on the quality of support delivery or the feedback and experience of participants. Concerns have also been raised about auditors not having the necessary capability and expertise to assess the quality of support delivery and promote quality improvement (also discussed in Section 3.1.4).[2350] As a result auditing is not considered to be an assurance of, or contributor to, quality – adding to perceptions from providers that there is limited value in registration.

> *"Audits are too preoccupied with items that relate to administration, policy compliance and reporting requirements that reveal little association to factors that influence the actual quality of service." – Family Advocacy[2351]*

Research has also identified concerns about audit approaches that are too focused on compliance approaches, rather than the consumer voice and observation of support delivery.

> *"Problems with reliance of paperwork are also illustrated by examples both in the UK and Australia where significant abuse and appalling practice has been found in supported accommodation services which have been audited in accordance with regulations and deemed to have met quality standards"* – Bigby [2352]

> *"...consideration should be given to revising the audit process to adopt methods known to be more adequate for monitoring service quality—such as observation and interview..."* – Dr Jade McEwen's submission to the Joint Standing Committee on the NDIS inquiry into the NDIS Commission[2353]

The auditing process should incorporate a greater focus on observing the quality of support delivery and elevating the voices of people with disability. This should include better engagement of people with disability as consumers in auditing to identify what is important to consumers in terms of quality improvement and ensure recommended improvements are informed by consumer feedback and experience.

> *"Critically, 'auditing' a disability support provider to make sure it is compliant with quality and safeguarding expectations must go beyond a review of documentation. Observation is much more important...[and] must include people visiting service sites to observe what happens there and to speak with service recipients. This is more likely to reveal the character of the service, much more so than the presence of relevant documentation."* – JFA Purple Orange [2354]

We note that the NDIS Commission is currently undertaking further work around auditing (also discussed in Section 3.1.4), including exploring a model for consumer technical experts (that is, people with lived experience of disability) to be involved in audits.[2355]

While we are supportive of this work, we believe further action is required to ensure audits are contributing to quality improvement by lifting the quality of auditing and expertise of auditors, building a stronger focus on observing and improving the quality of support delivery, and elevating the voices and experiences of people with disability.

The new National Disability Supports Quality and Safeguards Commission should also work in close collaboration with the Joint Accreditation System of Australia and New Zealand (JAS-ANZ), as the accreditor of auditors, to ensure a focus on the quality of support delivery and an understanding of the importance of properly including the voices of people with disability as consumers in the auditing process is embedded in the training, approval and oversight of auditors. [2356] This should ensure that all auditors approved by the new National Disability Supports Quality and Safeguards Commission have the capability to assess the quality of disability supports, rather than just the policies and procedures, of a provider, and that issues of auditing quality are addressed through ongoing monitoring of auditors.

Better targeted and scoped audits (see Section 3.1.5), and audit teams that include different sources of expertise (for example, consumer technical experts and new National Disability Supports Quality and Safeguards Commission staff) will also support these efforts.

We have also observed that audits undertaken once every 18 months to three years cannot be the only opportunity to consider and assess quality improvements. There must instead be a culture of continuous learning and improvement. The Deputy Commissioner for Quality should utilise provider outreach (informed and prioritised through data, monitoring of risk, and auditing reports) to proactively check-in with providers to monitor and advise on quality improvements (see Section 4.1.2 and Action 12.1), alongside capacity-building, outreach and auditing changes intended to lift the focus on continuous quality improvement.

4.2.3.   Action & Implementation Details

🗐 Action 12.2: The new National Disability Supports Quality and Safeguards Commission should make quality improvement a priority in capacity-building initiatives and audit processes

Initiatives should better support providers and workers to understand and focus on quality improvement. Efforts should be directed to more effective and targeted capacity-building initiatives and outreach with providers. The audit process should also be refocused on the quality of support delivery and the voice of people with disability, to support efforts to improve quality and build a continuous quality relationship in regulatory processes.

Implementation detail:

- The new National Disability Supports Quality and Safeguards Commission (led by the Deputy Commissioner for Quality and the new quality function) should enhance capacity-building initiatives for providers and workers to create a culture of continuous learning and improvement, informed by feedback and experience of people with disability, including through:

  - Delivering enhanced good practice guidance and training resources for providers and workers focused on good practice support delivery in different contexts and issues of concern (see Action 17.6), building on existing initiatives such as the NDIS Workforce Capability Framework. This should include clear and practical guidance that supports all providers and workers to deliver supports in line with the Practice Standards and Quality Indicators, as well as effectively implement human rights obligations under the UN Convention on the Rights of Persons with Disabilities.

  - Providing guidance to providers on strategies to seek and reflect on the feedback and experience of the people with disability they support, and sharing system-wide insights on feedback and experience of people with disability, to improve support design and delivery by providers.

- Creating an online 'Centre of Excellence' resource library, with research (including research commissioned by this function), guidance and advice on good practice models of support delivery that providers could adopt in different contexts. This should include collaboration with proposed research to understand culturally and racially diverse concepts of disability and care (see Action 2.2), the new Evidence Committee (see Action 23.2) and the new Disability Research and Evaluation Fund (see Action 23.3).

- Using the provider outreach function (see Action 12.1) to build provider capacity, including advising on quality improvement and disseminating good practice and innovative approaches.

- Facilitating industry collaboration forums and provider communities of practice to set expectations and share information about good practice.

- Delivering place-based educational and compliance awareness campaigns.

- Sharing insights and data about quality, drawing on regulatory intelligence and data reported by providers.

- The new National Disability Supports Quality and Safeguards Commission should improve the audit process to drive a renewed focus on quality and a culture of continuous quality improvement, including by:

  - Refocusing auditing on assessing good practice quality and observing support delivery, rather than reviewing policies, procedures and other forms of paperwork.

  - Embedding and elevating the voices of people with disability in the auditing approach, including better engagement with people with disability as consumers and ensuring quality improvements are informed by consumer experience.

  - Ensuring that the scope of audit is targeted and adapted to focus on specific aspects of provider quality where necessary.

  - Building on recent work to trial different models of auditing, such as including National Disability Supports Quality and Safeguards Commission staff and consumer technical experts (people with disability) in audit teams, and improving two-way flows of information between auditors and the new National Disability Supports Quality and Safeguards Commission.

  - Working with the Joint Accreditation System of Australia and New Zealand) to support the delivery of this improved auditing approach, including through training and guidance, approval, and monitoring of auditor performance.

4.3. Incentives to engage in quality improvement are limited, driven by a lack of measurement and transparency

The right foundations for quality supports and outcomes must be established by ensuring quality inputs through capacity-building, guidance and outreach that supports providers and workers to understand and deliver good quality supports (see Section 4.2.1 and Action 12.2); auditing that elevates the focus on quality and the voices of people with disability (see Section 4.2.2 and Action 12.2); and pricing and payments approaches that enable and encourage the provision of quality supports (see Chapter 4 and Recommendation 11). With these foundations established, focus should also be directed to transparency and measurement to incentivise providers to engage in quality improvement and support people with disability to be more active and informed consumers.

Currently, a lack of understanding and visibility of the relative quality of different providers means providers are not sufficiently incentivised to compete on quality to deliver fit-for-purpose supports to participants, or to improve or maintain their standing as good quality providers in the market. Participants also face challenges in understanding what good quality looks like and how their providers compare. Transparent assessment of providers against quality, safety and eventually outcomes metrics will both sharpen incentives for providers to engage in continuous quality improvement, and support consumer choice.

4.3.1. A lack of transparency limits incentives for providers to invest in and compete on quality, and presents barriers for people with disability to be active consumers in the market

As described above, poor understanding about quality and limited capacity-building amongst providers and workers is compounded by several other factors in contributing to a lack of incentives for providers to invest in quality and compete to deliver fit-for-purpose supports. This includes regulatory and pricing settings, and critically a lack of transparency about provider quality and performance.

With a lack of transparency, providers have no way of understanding how they are performing relative to other providers. A lack of benchmarking and visibility of performance also means there is limited imperative for providers to compete on quality by maintaining good performance or improving poor performance.

> *"A tighter working relationship between the NDIA and Commission, and a single source of truth for publishing provider performance data is required to better build provider capability, monitor performance and improve the supply of high-quality supports through proactive market management" – Provider* [2357]

This lack of transparency also means participants face challenges in understanding what quality supports should look like and how their providers compare to others. Participants face difficulties being active consumers in the market because of this lack of transparency and understanding, which in turn reduces incentives for competition between providers to deliver fit-for-purpose quality supports.[2358] We have heard that there has not been enough guidance for participants

around what a quality support should look like, as well as limited information to help participants choose between different supports and providers based on quality.

> *"...participants also lack access to important information that would allow them to meaningfully compare one provider to another within the approved service element in their package. Provider websites are generic and there is no 'star rating' or other guide to consumer satisfaction or independent quality measurement. Because the consumer's main source of information regarding service quality and performance is produced by the service provider themselves, there is a significant risk of bias or selectivity in these choices." – Considine [2359]*

> *"For those without co-ordinators, carers often put in difficult situation of trying to navigate and find services. This is a hit and miss lucky dip scenario, where one has no idea of the quality of service." – Non-government organisation[2360]*

4.3.2. There should be transparent assessment and measurement of provider performance to encourage quality improvement and competition by providers, and inform consumer choice

To address this lack of transparency and understanding, and sharpen incentives for providers to invest in and compete on quality, the performance of providers must be measured and published. We have received submissions putting forward ideas about how quality could be better assessed, with this assessment leading to overall ratings that can be used to benchmark providers and inform the choices participants make.

> *"The [Review] should consider... a fit-for-purpose performance monitoring framework, indicators, and ratings scale that: is transparent and easy for participants and their representatives to understand..." – Provider [2361]*

> *"[Agencies] could play a stronger role in benchmarking quality service delivery across specific high use services/settings to provide additional guidance to providers of what quality looks like." - Occupational Therapy Australia [2362]*

A Provider Performance Framework should be developed and used to assess providers against metrics of quality, safety and eventually outcomes. These metrics should capture a range of dimensions (including the voices and perspectives of people with disability), and be designed in partnership with people with disability. Quality and safety metrics could include surveys of consumers' experiences, information about a provider's regulatory compliance history, and other indicators of quality (such as the efficacy of supports in maintaining or improving quality of life and meeting the human rights of people with disability, the compassion and responsiveness of support delivery in meeting the needs of people with disability, the way an organisation is led, and innovation in support delivery). Over time, metrics that assess the contribution of providers to participant-level and scheme-level outcomes should also be incorporated and be integrated with the new Disability Supports Outcomes Framework (see Action 23.1).

Informed by research, we think that performance measurement and publication will be most valuable in changing provider behaviour, by making providers more aware of their performance relative to other providers in the market and incentivising them to take action to improve their performance and quality.[2363] However, we note that research has shown mixed results regarding the use of such provider performance assessments and ratings by consumers.[2364] While recognising the primary intent to change provider behaviour, it will be important for metrics to be designed in consultation with people with disability to ensure their voices are heard and that metrics measure the aspects of quality that matter most to people with disability.

Once the Provider Performance Framework is developed, assessments against these quality, safety and outcomes metrics should be published in a transparent and accessible manner, including on the new centralised online platform (see Action 10.1). These assessments should be objective and independent, reflecting both improvements and declines in performance across metrics over time.[2365] These assessments should also be published in a way that is accessible and useful in supporting consumer choices about providers (noting that these assessments will not be the only factor informing their choices). Publication of assessments will also assist Navigators (see Recommendation 4) to support people with disability to make informed choices by identifying and comparing providers in their local area based on quality.

Once the assessment and measurement approach has matured, depending on the results, consideration should be given to ways to incorporate consequences for good and bad performance. For example, good performance could be a key consideration in selecting providers to deliver supports under approaches such as preferred provider lists (see Action 11.2), provider panel arrangements (see Action 13.2) and alternative commissioning approaches (see Recommendation 14). Intelligence gathered about poor performing providers should inform the new National Disability Supports Quality and Safeguards Commission's regulatory activities and risk-proportionate approach. Case Study 30 provides examples of comparable human services systems that assess the performance of providers and publish these performance assessments. These approaches could inform the design of the Provider Performance Framework, metrics for disability support providers, and the approach to publishing assessments.

> **Case Study 30: Provider performance assessment and ratings**
>
> *Care Quality Commission (CQC)[2366]*
>
> The CQC is the independent regulator of health and adult social care in England. The CQC monitors, inspects and regulates services and publishes findings. It assesses services against five key questions:
>
> - Are they safe?
> - Are they effective?
> - Are they caring?
> - Are they responsive to people's needs?

- Are they well-led?

Results are reflected in a four-point rating scale (outstanding, good, requires improvement and inadequate) and published on the CQC's website.

The CQC's website has a directory where recipients can find and compare services in their area, which includes ratings against each of the five key indicators and the full inspection report. Providers are also required to display these ratings (for example, on their websites and in care homes).

Residential Aged Care[2367]

The Department of Health and Aged Care, based on a recommendation of the Royal Commission into Aged Care Quality and Safety, has developed and publishes 'star ratings' on residential aged care providers. Performance is measured against four categories:

- Compliance – based on non-compliance decisions made by the Aged Care Quality and Safety Commission reported daily.

- Residents' experience – at least 10 per cent of older Australians living in residential aged care homes are interviewed face-to-face about their overall experience at their residential aged care home by a third-party vendor annually.

- Staffing minutes – derived from reporting under the Quarterly Financial Report and Annual Financial report, case-mix adjusted through the Australian National Aged Care Classification and reported quarterly.

- Quality measures – data on five existing quality indicators (pressure injuries, physical restraint, unplanned weight loss, falls and major injury, and medication management) reported quarterly.

Results are reflecting in a five-point star rating (excellent, good, acceptable, improvement needed and significant improvement needed). Providers receive a star rating for each category, and an overall star rating.

Ratings are published online, including as part of the MyAgedCare website, which allows consumers to search providers.

4.3.3.   Action & Implementation Details

⬛ **Action 12.3: The new National Disability Supports Quality and Safeguards Commission, working with the Department of Social Services, should design, test and implement an approach to measure and publish metrics of registered provider performance**

This should include an initial focus on quality and safety and be designed to incentivise improvements by providers and drive greater competition on quality. It should be supported by accessible and useful information to support people with disability in making choices

about providers. Over time, this should incorporate measurement of outcomes, and be accompanied by consequences for good and poor performance.

Implementation detail:

- The Department of Social Services (DSS) and the new National Disability Supports Quality and Safeguards Commission should develop a Provider Performance Framework to measure the performance of registered providers against metrics of quality and safety. In developing this Provider Performance Framework, proposed metrics should be designed and tested, including through consultation with providers and people with disability.

  - These metrics should initially focus on indicators of quality and safety, with further work over time to consider measuring the contribution of providers to individual-level and scheme-level outcomes (see Action 23.1, noting that any outcome measures and reporting for providers should be integrated with the new Disability Support Outcomes Framework).

  - Quality and safety metrics should draw on approaches in similar human services systems, and could include metrics such as surveys of consumers' experiences, information about a provider's regulatory compliance history, and other indicators of quality. Other indicators of quality could include the efficacy of supports in maintaining or improving quality of life and meeting the human rights of people with disability, the compassion and responsiveness of support delivery in meeting the needs of people with disability, the way an organisation is led, and innovation in support delivery.

  - Further consideration should be given to whether the same metrics or more tailored metrics should be applied to different types of providers and supports.

  - Further consideration should be given to sequencing in the roll out of a measurement approach (for example, initially focusing on certain types of supports).

- DSS and the new National Disability Supports Quality and Safeguards Commission should publish assessments of registered provider performance against these metrics, once the Provider Performance Framework and measurement approach has been developed and tested.

  - This assessment should be published in an easily accessible form, including on the new centralised online platform (see Action 10.1). This should support people with disability in choosing supports (for example, being published in a way that would allow consumers to search for providers based on factors such as support type and location). It should also clearly benchmark providers, in order to motivate quality improvements.

- DSS and the new National Disability Supports Quality and Safeguards Commission should, over time, develop consequences for good and poor provider performance.

- While the measurement approach is still maturing, consequences will flow from consumers making choices about providers and supports based on this information. Where poor performance involves breaches of providers' regulatory obligations, consequences will also flow from appropriate regulatory compliance action being taken.

- Once the measurement approach has matured, consideration should be given to additional ways to incorporate consequences. For example, a good performance could be a key consideration in selecting providers to deliver supports under approaches such as preferred provider lists (see Action 11.2), provider panel arrangements (see Action 13.2) and alternative commissioning approaches (see Recommendation 14).

- Intelligence gathered about poor performing providers should inform the new National Disability Supports Quality and Safeguards Commission's regulatory activities, as part of a more risk-proportionate approach to monitoring and oversight of the whole provider market (see Recommendation 17).

5. Reduction and elimination in the use of restrictive practices

A warning to readers: This section contains discussion of restrictive practices and abuse and violence experienced by people with disability. The content is upsetting for all but may also be triggering for some. There are contact details to access support at the beginning of this report.

- Reducing and eliminating the use of restrictive practices against people with disability is critical to protecting the rights and enhancing the quality of life of people with disability, as well as to meeting Australia's obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). All Australian governments committed to this task by agreeing to the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector in 2014.

- The establishment of the NDIS Quality and Safeguards Commission (NDIS Commission) has strengthened the focus on reducing and eliminating restrictive practices and put in place the regulatory framework to increase adoption of behaviour support planning and drive down the use of restrictive practices. Important progress has been made in raising awareness of what restrictive practices are and how behaviour support planning can lead to better quality of life; providing greater visibility of the prevalence of the use of restrictive practices in the delivery of disability supports; and building the capability of the market to undertake behaviour support planning. However, despite the declarations and actions of governments so far, restrictive

practices – both authorised and unauthorised – continue to be used against people with disability, including in the NDIS.

- Government actions have not been sufficiently coordinated. Differences in requirements between jurisdictions and a lack of information sharing have created confusion and frustration across the system, ultimately hindering the coordinated action needed. Even when rules are in place, they are inconsistently enforced, with insufficient corrective action against providers inappropriately or illegally applying restrictive practices and little encouragement to providers to reduce their use of restrictive practices.

- Despite the importance of behaviour support planning in reducing and eliminating restrictive practices, the quality of behaviour support plans is generally low. This can mean behaviours of concern are not addressed and reliance on restrictive practices continues. In addition, providers who implement behaviour support plans have generally placed greater focus on meeting regulatory requirements around authorisation and reporting. In turn, this has meant less focus has been placed on improving practice quality and training workers to reduce the reliance on restrictive practices.

- It is essential that efforts to reduce and eliminate restrictive practices are reinvigorated across all parts of the system. Government agencies must work together to implement and enforce consistent regulatory frameworks and support quality improvements across behaviour support planning and implementation. Providers and workers must be supported to change an entrenched culture of restrictive practice usage, and people with lived experience of restrictive practices must be involved in these processes.

Recommendation 18: Reinvigorate efforts to urgently drive reduction and elimination in the use of restrictive practices

🗐 Legislative change required

- 🗐 Action 18.1: All Australian governments should agree a joint action plan for meaningful collaboration and a stronger focus on corrective actions against providers to reduce and eliminate restrictive practices, and review interventions and practices that may be harmful.
- Action 18.2: The new National Disability Supports Quality and Safeguards Commission, working with other agencies as relevant, should work with behaviour support practitioners and providers to urgently improve the quality of behaviour support plans, enhance quality of life for participants and eliminate poor provider practices.
- Action 18.3: The new National Disability Supports Quality and Safeguards Commission, working with state and territory agencies, should better support providers to deliver on their role in reducing and eliminating restrictive practices.

5.1. Efforts across governments have not made sufficient progress in reducing and eliminating the use of restrictive practices

The use of restrictive practices in disability services remains widespread, continuing to breach the human rights of people with disability. All Australian governments have committed to reducing and eliminating the use of restrictive practices against people with disability in line with their obligations to protect the rights and dignity of people with disability under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).[2368] However, progress against this ambition has been slow, including within the NDIS.

Governments must take a stronger and more consistent approach to the way they regulate the use of restrictive practices and behaviour support to reduce harmful practices and bring meaningful change to the lives of people with disability affected by them. This must include efficient and effective information sharing and systems for collecting data on the use of these practices and for monitoring reduction, as well as stronger corrective action in response to providers inappropriately or illegally applying restrictive practices.

5.1.1. There continue to be reports showing high usage of restrictive practices by providers in the services delivered to participants

Restrictive practices are practices or interventions that restrict the freedom of movement or rights of a person with disability.[2369] Restrictive practices are often used in response to behaviours displayed by a person with disability that others interpret as posing a risk, either to the person with disability or other people around them (often referred to as 'behaviours of concern').[2370]

There is a long history of people with disability – particularly people with Autism, intellectual disability and psychosocial disability – being subject to restrictive practices, with little regard for the rights and dignity of the person against whom they are being used.[2371]

> *"Restrictive practices are at odds with the human rights of people with disability and represent a significant form of violence and coercion" – Disability Royal Commission Research Report*[2372]

Through a rights-based lens, it is important to recognise the experiences of people facing intersectional discrimination and inequality. Particularly in the context of examining restrictive practices, several studies have suggested that people facing intersectional discrimination and inequality are at higher risk of restrictive practices being used against them.[2373]

There are several types of restrictive practices regulated in the NDIS through *National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018* (NDIS Restrictive Practices and Behaviour Support Rules) under the *National Disability Insurance Scheme Act 2013* (NDIS Act), with chemical and environmental restraints the most commonly used.[2374] Figure 164 provides an overview of these regulated restrictive practices and their use in the NDIS, noting that these categories do not cover all forms of restrictive practices, only those regulated by the NDIS Commission in disability services.[2375]

Figure 164: Types and prevalence of regulated restrictive practices in the NDIS[2376]

Type	Definition	Number of NDIS participants associated with regulated restrictive practice notifications (April to June 2023)
Seclusion	The sole confinement of a person with disability in a room or a physical space at any hour of the day or night where voluntary exit is prevented, or not facilitated, or it is implied that voluntary exit is not permitted.	585
Chemical restraint	The use of medication or chemical substance for the primary purpose of influencing a person's behaviour. It does not include the use of medication prescribed by a medical practitioner to treat, or to enable the treatment of, a diagnosed mental disorder, physical illness or physical condition.	7,930
Mechanical restraint	The use of a device to prevent, restrict, or subdue a person's movement for the primary purpose of influencing a person's behaviour. Mechanical restraint does not include the use of devices for therapeutic or non-behavioural purposes.	1,718
Physical restraint	The use or action of physical force to prevent, restrict or subdue movement of a person's body, or part of their body, for the primary purpose of influencing their behaviour. Physical restraint does not include the use of a hands-on technique in a reflexive way to guide or redirect a person away from potential harm/injury, consistent with what could reasonably be considered the exercise of care towards a person.	1,817
Environmental restraint	The restriction of a person's free access to all parts of their environment, including items or activities.	7,659

All Australian governments have agreed to principles and strategies to encourage the reduction of these practices in disability supports, in line with their obligations under the UNCRPD. In the NDIS, efforts have been led by the NDIS Commission in partnership with state and territory authorities. These efforts have resulted in more data being available on the use of these practices than ever before, as well as the creation of a regulatory framework to drive reduction in the use of restrictive practices and guidance and resources for improving behaviour support.

However, despite these efforts, the use of restrictive practices, and particularly unauthorised use, remains persistently and disturbingly high. Data collected gives a picture of the extent of widespread routine use of restrictive practices in the delivery of NDIS supports, and in particular the use of unauthorised restrictive practices.

In the 2021-22 financial year alone, over 1.4 million individual instances of unauthorised restrictive practices were reported, while over 5.5 million uses of restrictive practices covered by a behaviour support plan were reported.[2377] Overall, around 2.1 per cent of all participants are currently subjected to regulated restrictive practices, either unauthorised or practices covered by a behaviour support plan (12,717 participants reported in April to June 2023).[2378]

Chemical and environmental restraint account for the vast majority of both reported unauthorised restrictive practices and restrictive practices covered by a behaviour support plan. For example, in 2021-22, around 47 per cent of unauthorised restrictive practices were chemical restraints, and around 46 per cent were environmental.[2379] Similarly, in the same period, for restrictive practices covered by a behaviour support plan, around 52 per cent of restrictive practices covered by a behaviour support plan were chemical restraints and around 41 per cent were environmental restraints. [2380]

The Disability Royal Commission's research report on restrictive practices found several key drivers for the ongoing usage of these practices.[2381] These drivers include the ongoing reliance in the NDIS on services being provided in institutional settings segregated from mainstream society; workplace culture and perceptions of obligations (for example, work health and safety obligations and insurance expectations to limit risk to others); under-resourced services; and societal attitudes towards people with disability.

The Disability Royal Commission also noted the impact of current legal frameworks in permitting these practices to occur without support for the person experiencing them, as well as inadequate responses to providers using such practices without authorisation. Responses to the Disability Royal Commission's issues paper on restrictive practices identified other drivers including a failure to recognise and respond effectively to the needs of people with disability, and a lack of resources and training to support workers and providers in reducing the use of restrictive practices. [2382]

The key regulatory strategy for reducing and eliminating restrictive practices in the NDIS is the requirement for providers to have all use of restrictive practices authorised in accordance with state and territory requirements and documented in a behaviour support plan (BSP) produced by an approved behaviour support practitioner and lodged with the NDIS Commission (discussed in more detail in Section 5.2 below). The intention of this approach is to focus efforts on the

development of non-restrictive approaches to understanding, preventing and responding to behaviours of concern.[2383]

Based on what we have heard in consultation and engagement, and consistent with what the Disability Royal Commission's work identified, we believe these steps have not done enough to address the continued high usage of restrictive practices.[2384]

> *"Behaviours that need to be corrected have to wait months (in one case years) for a behavioural support plan, and getting that BSP modified takes weeks or months. It significantly increases the work of the daily support provider, and drastically elevates the risks to the front-line support workers" – Nganana Inc[2385]*

The persistent use of restrictive practices reflected in the data described above represents continued breaches of human rights for people with disability. This is unacceptable and it is imperative that action is taken to remediate these risks to the safety, rights and dignity of people with disability. The Disability Royal Commission made several comments in this area, including proposals to improve the legal framework for authorising these practices, improving access to behaviour support planning, and recognising the impact of environmental factors such as unsuitable accommodation and living arrangements in the ongoing use of restrictive practices.[2386]

We agree, and identify additional steps that can be taken to meaningfully reduce these practices in our recommendation above and detailed actions below. There are also measures that can be taken to reduce some of the drivers of the usage of restrictive practices, such as unsuitable accommodation and environments, which are considered in other recommendations we are making (for example, see Recommendations 8 and 9 on housing and living).

5.1.2. Implementation of the shared regulatory oversight model lacks the consistency, collaboration and information sharing needed to reduce and eliminate the use of restrictive practices

The Australian Government and state and territory governments all play roles in the regulation and monitoring of restrictive practices, including where they are used in services delivered to participants (see Box 94). This shared regulatory oversight model has been developed through a series of agreements between governments on the principles and strategies for the reduction and elimination of restrictive practices in disability services, including:

- The National Framework for Reducing and Eliminating Restrictive Practices in the Disability Service Sector – agreed by the then Disability Reform Council in 2014.[2387]
- A national list of prohibited practices – endorsed by the then Disability Reform Council in 2019.[2388]
- The Principles for Nationally Consistent Authorisation of Restrictive Practices – supported or supported in-principle by the then Disability Reform Council in 2020.[2389]

Box 94: Government roles and responsibilities for restrictive practices and behaviour support in the NDIS[2390]

The NDIS Quality and Safeguards Commission (NDIS Commission):

- Enforces requirements for NDIS providers delivering behaviour support assessments and plans or implementing restrictive practices to be registered.
- Receives reports of use of unauthorised restrictive practices, as well as monthly reports of use of restrictive practices contained in a behaviour support plan (registered providers only).
- Assesses the suitability of behaviour support practitioners.
- Receives behaviour support plans containing restrictive practices that are lodged by providers.
- Monitors compliance with registration requirements for providers to seek authorisation to use restrictive practices and develop a behaviour support plan.
- Provides guidance and policies on delivery of high quality behavior support plans and reductions in restrictive practices.
- Takes regulatory action against providers in breach of their obligations under the NDIS Act.
- Encourages coordination between state and territory authorities on restrictive practice authorisation and monitoring.

State and territory authorities:

- Receive reports of unauthorised and authorised restrictive practices (depending on state/territory rules).
- Administer processes for authorising the use of restrictive practices, including reviewing behavior support plans (depending on state/territory rules).
- Take regulatory action against providers who are in breach of their obligations under state/territory law.
- Provide guidance and policies on the delivery of restrictive practices and reduction in their use.

The National Disability Insurance Agency (NDIA):

- Provides plan funding for the development and implementation of quality behaviour support plans.
- Assesses requests for funded supports intended to address behaviours of concern (for example, home modifications in response to a behaviour).

However, this series of agreements between governments has focused heavily on the establishment of a regulatory framework for authorising and reporting on the use of restrictive practices, with limited progress in reducing and eliminating their use.

Even with this focus on establishing the regulatory framework, there remains limited consistency, coordination and collaboration across the system, which manifests in a range of ways. Particular areas of inconsistency include the implementation of authorisation processes (described in Section 5.1.3) and the prohibition of harmful practices (described in Section 5.1.5).

One key outcome of this lack of consistency, coordination and collaboration is shortcomings in reporting and information sharing across the shared regulatory oversight model. State and territory authorities have raised concerns about insufficient sharing of information from the NDIS Commission to support their roles in the system.[2391] Providers have also identified the lack of information sharing and resulting duplication in reporting requirements as a key pain point – with requirements to report the same or very similar information to both the NDIS Commission and state and territory authorities, as well as to report the same information to the NDIS Commission multiple times (for example, the obligation to report the same use of a restrictive practice to the NDIS Commission both as a reportable incident and as part of a monthly report).[2392]

These inconsistencies and a lack of coordination and information sharing cause frustration for providers, who often find themselves needing to report the same incident multiple times due to a lack of interaction between these systems. This is compounded by variations in the definition of restrictive practices between different jurisdictions, creating confusion for providers and participants about what sorts of restrictive practices are regulated in each jurisdiction.[2393] Those working across borders or in multiple systems within the same jurisdiction (for example, providers that offer aged care and NDIS services) may need to tailor their organisational policies to each jurisdiction's specific articulation,[2394] and face differing (and at times seemingly contradictory) obligations between different systems.

The complexity introduced by these issues is antithetical to best practice regulation, which discourages overlaps, gaps and inconsistencies as they tend to foster poorer compliance.[2395] The complexity and duplication also means providers must direct their efforts towards meeting administrative requirements, which diverts resources and attention from improving the quality of life of the participants that they support and ultimately reducing and eliminating their use of restrictive practices.

> *"Differences across states/territories both within the Framework and then relationships between the Framework and state/territory based authorising bodies leading to inconsistency and confusion, which can mean vulnerable people "fall through the cracks" – Non-government organisation[2396]*

> *"The differing information that NDIS and [the state senior practitioner] provide disability organizations on Restrictive practices and Behavior support planning. when the two departments meet with an organization and openly argue with each other*

during a meeting, and both parties blatantly telling you to do what they say. puts an organization in a difficult position" – Non-government organisation[2397]

We believe there needs to be an approach that makes the most of the information already being gathered across the different systems that regulate restrictive practices. This would reduce the burden on service providers needing to report and tailor approaches to a variety of systems, and enhance the role information can play in collaboration between agencies to reduce restrictive practice usage.

Information sharing arrangements and protocols should be put in place between the NDIS Commission and each state and territory authorising agency to ensure referrals and data can be shared easily. This should include sharing information relating to unauthorised restrictive practices, behaviour support plans and reporting against the outcomes of these plans between all relevant agencies. This would encourage and enable more collaboration between jurisdictions; support agencies to take corrective action against providers where appropriate; enhance the ability of all agencies to provide more useful and targeted resources and support to providers on reducing restrictive practices; and enable streamlined reporting requirements for service providers operating across jurisdictions and systems.

To achieve improved coordination, we also recognise the need to enhance the distinct role that states and territories play. State and territory authorities are well-positioned to play a significant role in supporting the reduction and elimination of restrictive practices. They generally have stronger connections, or avenues for connecting, with the local community and their circumstances; have greater capacity to adapt to the nuances of the jurisdiction; and are often better placed to respond quickly and resolve matters. They also generally have responsibilities for overseeing other systems in which restrictive practices are commonly used, such as education, mental health and corrections. Therefore, the current model of shared regulatory oversight appropriately allocates responsibilities, with states and territories having a more direct role in taking action against unauthorised restrictive practices.

However, to address the divergent approaches that have emerged between different states and territories, a more closely coordinated and consistent approach is needed. Improving these approaches will ensure that efforts to reduce the use of restrictive practices will make a meaningful impact.

Finally, greater coordination and consistency between jurisdictions also requires more collaboration with practitioners and other sectors to ensure the development of consistent approaches that are focused on quality of life. For example, we have heard that there is sometimes confusion and uncertainty around whether some medications prescribed by treating practitioners should be considered chemical restraints.[2398] This reflects the lack of a nationally consistent approach to authorisation and monitoring of restrictive practices broader than just disability, and the need for measures to be taken to clarify issues where the work of different systems intersect (for example, medical, disability, education).

With its legislative function to provide leadership in the reduction and elimination of restrictive practices – including developing guidance and policy on reducing the use of restrictive practices by providers and assisting in developing regulatory frameworks – the new National Disability Supports Quality and Safeguards Commission should lead efforts to address this uncertainty around chemical restraints.[2399] It should do so through regular engagement with both the sector and people with lived experience of these medications.

5.1.3.   Some jurisdictions have failed to implement nationally agreed approaches to the authorisation of restrictive practices

In 2014, all Australian governments agreed to the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector, which included commitments to ensure people have access to nationally consistent protections in relation to the use of restrictive practices.[2400] A key part of efforts to achieve greater national consistency was the development of the Principles for Nationally Consistent Authorisation of Restrictive Practices (the Authorisation Principles), which were supported by the then Disability Reform Council in July 2020.[2401] The Authorisation Principles set out the respective functions of the NDIS Commission and state and territory authorities in the authorisation and monitoring of restrictive practices.[2402]

However, the Authorisation Principles have not yet been fully implemented and the authorisation practices of each state and territory differ. Currently, authorisation processes in only four states and territories (Victoria, South Australia, the Northern Territory and the Australian Capital Territory) are considered to be fully aligned with the Authorisation Principles, with the remainder considered to be only partially aligned.[2403] These inconsistencies and the failure to fully implement the Authorisation Principles in a timely way create additional risk for people with disability who are already at significant risk of violence, abuse, neglect and exploitation, and of having a poor quality of life.

The slow progress on implementation has also led to confusion for providers and behaviour support practitioners who are seeking to meet their regulatory and reporting obligations and reduce the use of restrictive practices, as different agencies have different views on what is considered a restrictive practice and different obligations for authorisation and reporting relating to these practices. Similar issues have arisen in the way rules are applied for prohibited practices (see Section 5.1.5) and in how positive behaviour support plans are monitored.

To address these issues, states and territories must prioritise legislating and implementing consistent authorisation processes in line with the Authorisation Principles. This should include use of the Senior Practitioner model, which is currently the most common approach. Victoria, the Australian Capital Territory and the Northern Territory have enacted legislation implementing the Senior Practitioner model with minor differences, while Tasmania is currently consulting on legislation that includes this model.

We consider that the Senior Practitioner model is preferable as it provides additional safeguards for those subject to restrictive practices. This aligns with the approach recommended by the Disability

Royal Commission (Recommendation 6.35).[2404] Some of the key characteristics and benefits of this model are:

- There is a single point of authorisation and additional quality assurance processes (such as review of the behaviour support plan).
- The person themselves or their representative is actively involved in decision-making.
- There is no requirement for consent to the restrictive practice. Consent requirements can lead to lengthy delays, and create a perverse situation where a person may be giving approval for their provider to breach their own human rights.
- The decision is appealable, often at the civil and administrative appeals agency in the state or territory.
- Additional enforcement powers within the legislation for a Senior Practitioner model allow for corrective actions to be enforced at the state and territory level.

5.1.4. Corrective actions are focused too heavily on reporting compliance, and instead need to provide a stronger deterrence to the failure to engage in efforts to reduce and eliminate restrictive practices

Since its establishment, the NDIS Commission has developed a number of mechanisms for reporting and monitoring on the use of restrictive practices by registered NDIS providers. These include reportable incidents, the requirement to lodge behaviour support plans and the requirement to report on their implementation monthly.[2405] Data collected through reporting gives a picture of the widespread routine use of restrictive practices in the NDIS – in some cases without implementing appropriate behaviour support planning.[2406]

However, current regulatory activity at the national level has focused on awareness raising and collecting reports of unauthorised restrictive practice (URP) use, rather than using this regulatory intelligence to inform general and risk-based approaches for reducing restrictive practice usage.

In a new regulatory environment, it may be appropriate for compliance reporting to be a focus for the regulator. However, this often results in providers being overly concerned with meeting the reporting requirements, rather than focusing their efforts on providing quality support to participants and improving a participant's quality of life and outcomes. With regulatory arrangements now well established in the NDIS, it is critical that the compliance approach adjusts to make a real impact in reducing restrictive practice use.

Pursuing compliance and enforcement action more assertively against providers relating to the unauthorised or inappropriate use of restrictive practices would create stronger deterrents for providers from using restrictive practices. Publicising the outcomes of investigations and prosecutions would further strengthen the deterrent effect. In many cases, the NDIS Commission and state and territory authorities will need to collaborate in pursuing this action.

As shown in Figure 165, the high level of URP usage is concerning. URP usage in the NDIS – both by providers who are not currently registered, and registered providers who continue to employ high levels of URPs without appropriately implementing behaviour support planning – must be a

priority for compliance and enforcement activities, as part of a risk-based approach designed to have the maximum positive impact.

Figure 165: Growth in the use of unauthorised restrictive practices between 1 July 2019 and 30 June 2022[2407]

	2019-20	2020-21	2021-22
Number of participants subject to unauthorised restrictive practices (URP)	4,140	7,532	8,830
Number of URPs	289,417	903,018	1,422,295

Recently, the NDIS Commission has begun to target compliance activity to cases where individual participants have been subject to high levels of use of URPs.[2408]

> *"[After the NDIS Commission's engagement and compliance activity] compliance had been achieved for 178 (89%) of the participants and resulted in the finalisation of 283,236 (90%) of the URPs. Finalisation of URPs can occur where a regulated restricted practice becomes authorised (if required) and included in a Behaviour Support Plan, or where the practice has ceased." – NDIS Commission report on unauthorised restrictive practices[2409]*

While this approach has yielded results through supporting individual providers to regularise their compliance with the NDIS Restrictive Practices and Behaviour Support Rules, it has not been enough to change the broader culture among providers to embed quality behaviour support planning and to drive down the use of restrictive practices.[2410] There are some, albeit early, indications that the numbers of URPs have stabilised. For example, comparing the period from April to June 2022 with April to June 2023, the proportion of participants associated with unauthorised restrictive practice notifications declined as a proportion of the total number of participants and the growth in the number of notifications slowed.[2411] However, sustained and much stronger efforts will be required.

Despite the fact that all providers who implement regulated restrictive practices are required to be registered, we have heard concerns that there is a growing issue of regulated restrictive practices being used unlawfully by unregistered providers that may not be aware this is what they are doing.[2412] The scale of this issue is clouded by the lack of data on unregistered providers that hampers regulatory oversight more generally (see Section 3.1).

> *"It is highly likely that cases of restrictive practices are underreported. These practices are largely hidden from external sight, and some people subjected to restrictive practices in disability-specific settings may be unable to seek the advice and assistance that they need" – Legal Aid NSW[2413]*

"There are no incentives to report restrictive interventions, rather reporting is driven either by a genuine commitment to the safety, well-being, and development of the person or through fear of discovery that an unauthorised restraint has been used. In the current environment, only a complaint or audit would pick up inadequate reporting for restrictive interventions" – Non-government organisation[2414]

Going forward, the new National Disability Supports Quality and Safeguards Commission needs to apply a renewed focus on identifying and supporting all providers to understand and meet their obligations to reduce and eliminate restrictive practices. This will also enable it to better identify and support participants subject to these practices. This renewed focus will be aided by changes recommended in relation to registration (see Action 17.1), which will provide greater visibility of providers.

Where recurrent use of unauthorised restrictive practices persists, the new National Disability Supports Quality and Safeguards Commission should take enforcement action against providers. In particular, focus should be directed towards providers that are not implementing behaviour support plans and continuing to use high levels of URPs, using prohibited restrictive practices (see Section 5.1.5), or remaining unregistered to deliver restrictive practices and behaviour support. These providers should face strong enforcement action to effectively deter such market behaviour.

Enhanced cooperation between the new National Disability Supports Quality and Safeguards Commission and state and territory authorities will be necessary to deliver a more coordinated approach that uses the regulatory levers available at each level of government effectively to apply corrective actions that drive reductions in restrictive practice usage.

5.1.5.   A stronger approach is required to respond to the continued use of practices that are harmful to people with disability

We have heard concerns about persistent use of practices that have been recognised as being harmful to people with disability. We are of the clear view that stronger action must be taken to urgently eliminate these practices.

In December 2019, the then Disability Reform Council endorsed a national list of prohibited practices.[2415] Prohibited practices are types of restrictive practices that are harmful and should never be used against a person with disability. These include specific forms of physical restraint that are associated with adverse and catastrophic consequences such as long term psychological or physical injury or death, as well as punitive and aversive strategies (for example, positive and negative punishment that constitutes emotional, psychological and/or social abuse of a participant). These practices are not aligned with contemporary positive behaviour support approaches and are unethical. The NDIS Commission has supported this agreement with a Position Statement that describes its views on these and other high risk practices.[2416]

States and territories are responsible for the enforcement of these prohibitions, while the NDIS Commission has a legislative function to support states and territories to improve consistency on these issues.[2417] However, states and territories have made different levels of progress towards

prohibiting these practices in legislation, and do not consistently have legal frameworks and enforcement mechanisms to enable corrective action to be taken when providers use these practices.[2418] Further, the information available about what practices are prohibited can be unclear or inconsistent. This creates confusion for providers about their obligations, and in turn can leave participants unprotected against practices that have been nationally recognised as dangerous and needing to be banned. We have also heard of instances in which providers have been advised by behaviour support practitioners to employ prohibited practices, such as bear hugs and aversive holds.[2419]

Noting that all Australian governments have agreed on the danger of continuing usage of prohibited practices, urgent action is needed. States and territory authorities must have appropriate legislative frameworks that enable them to monitor and take action against the use of prohibited practices, so they can effectively protect the rights of people with disability in their jurisdiction. There should also be greater cooperation between the new National Disability Supports Quality and Safeguards Commission and state and territory authorities in pursuing strong corrective action against providers using these practices. In addition, all relevant authorities should work together closely to ensure consistent information is available to participants, providers and workers about what practices are prohibited.

We have also heard particular concerns about certain behavioural interventions and practices that may be harmful to people with disability or have significant risks of unintended consequences (such as some interventions and practices under Applied Behaviour Analysis). We have heard concerns that these interventions and practices may not be neurodiversity affirming, strengths based, or consistent with the social model of disability and relevant human rights norms underpinning the NDIS. We have also heard concerns about the current evidence base underpinning these interventions and practices, and whether it is sufficiently robust to suggest they are sufficiently net beneficial, safe and cost effective in many instances. We share these concerns, and believe that detailed and comprehensive consideration of these issues is required as a matter of priority.

We note that some of these interventions and practices may already be considered prohibited practices (for example, punitive strategies involving punishment) – reinforcing the need for urgent action to legislatively ban prohibited practices (consistent with the existing agreement) as well as for an assertive approach to be taken by all relevant authorities in pursuing strong corrective action.

Alongside this, the new National Disability Supports Quality and Safeguards Commission and the new NDIS Evidence Committee (see Action 23.2) should undertake comprehensive work, including consulting with people with disability, practitioners, providers, researchers and other experts, to review these behavioural interventions and practices. This work should be undertaken with a view to providing advice to governments on whether any of these interventions and practices should not be funded through the NDIS and/or should be added to the agreed national list of prohibited practices.

5.1.6. Action & Implementation Details

📑 Action 18.1: All Australian governments should agree a joint action plan for meaningful collaboration and a stronger focus on corrective actions against providers to reduce and eliminate restrictive practices, and review interventions and practices that may be harmful

This should align with the objectives and commitments of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector. This should include immediate action to operationalise information sharing on restrictive practices, adopt best-practice and nationally consistent authorisation arrangements, and ban prohibited practices in order to achieve safer outcomes for people with disability. It should also include taking stronger compliance action against providers inappropriately and/or illegally applying restrictive practices. In addition, the new National Disability Supports Quality and Safeguards Commission and the new NDIS Evidence Committee (see Action 23.2) should review interventions and practices that may be harmful to people with disability.

Implementation detail:

- The Disability Reform Ministerial Council should agree a joint action plan to support greater collaboration and a stronger focus on reducing and eliminating the use of restrictive practices. It should encompass the priority issues and activities identified below, and provide for regular monitoring and reporting on progress.

- The new National Disability Supports Quality and Safeguards Commission should clearly articulate and operationalise information sharing protocols with respect to restrictive practices with all relevant state and territory authorities and include relevant state and territory authorities in the Prescribed Bodies Rule (see Action 19.2) to support information sharing.

  - Information to be shared should include reporting of unauthorised restrictive practices, behaviour support plans lodged with the new National Disability Supports Quality and Safeguards Commission and reporting against those plans.

- The new National Disability Supports Quality and Safeguards Commission and state and territory authorities should increase national consistency through the following actions:

  - All states and territories should adopt the best practice model of authorisation, including using a Senior Practitioner, in line with the Principles for Nationally Consistent Authorisation of Restrictive Practices.

  - All states and territories should legislate to ban prohibited practices (as per the list endorsed by the Disability Reform Council in 2019) to ensure that these practices that are harmful for participants are not used and that strong action can be taken against anyone using them.

  - The new National Disability Supports Quality and Safeguards Commission, working with state and territory authorities, should continue to develop national positions on consistent clinical decision making and the categorisation of restrictive practices,

including by establishing a think tank on chemical restraint with the peak body for prescribing practitioners.

- The new National Disability Supports Quality and Safeguards Commission and the NDIS Evidence Committee (see Action 23.2) should undertake comprehensive work to review behavioural interventions and practices that may be harmful to people with disability, or where there may be insufficient evidence to suggest they are likely to be adequately net beneficial, safe and cost effective to warrant government subsidy (such as some interventions and practices under Applied Behaviour Analysis). This work should be undertaken with a view to providing advice to governments on whether any of these interventions or practices should not be funded through the NDIS, and/or should be added to the agreed national list of prohibited practices.

  - This work should be informed by significant consultation with people with disability, practitioners, providers, researchers and other experts.

- The new National Disability Supports Quality and Safeguards Commission in collaboration with state and territory authorities should use compliance and enforcement powers against the following activities, and publicise the outcomes of these investigations and prosecutions to strengthen the deterrence for providers from unauthorised and inappropriate use of restrictive practices:

  - Providers using prohibited practices;

  - Providers using restrictive practices who are not registered to implement restrictive practices; and

  - Providers continuing to employ high levels of unauthorised restrictive practices without implementing behaviour support planning and alternative behaviour support strategies.

- The new National Disability Supports Quality and Safeguards Commission should develop strategies to use data to:

  - Identify ways in which to target developmental interventions (to support providers to improve their practices) and corrective interventions (to respond to and deter providers inappropriately and/or illegally applying restrictive practices).

  - Measure the effectiveness of efforts by the new National Disability Supports Quality and Safeguards Commission and state and territory authorities in reducing the use of restrictive practices, improving provider behaviour support practice and enhancing the quality of life of affected participants.

  - Key measures of effectiveness should be included in the Disability Supports Outcomes Framework (see Action 23.1), and monitored and reported on by the Disability Outcomes Council (see Action 20.5).

- Publish metrics regularly to enable providers to benchmark their behaviour support practice against equivalent providers and drive continuous improvement.

5.2. Greater effort is needed to improve the quality of behaviour support plans

While behaviour support is more than just preparing a behaviour support plan (BSP), the quality of the BSP is integral to the ultimate experience of the affected participant. A good quality BSP is associated with improved outcomes, better quality of life and reduced use of restrictive practices, while a poor quality BSP can perpetuate poor outcomes, low quality of life and greater use of restrictive practices.

Since 2021, all BSPs for participants that include restrictive practices have been required to be lodged with the NDIS Commission. Now that this oversight scheme is established nationally, it is vital to step up efforts with targeted action in areas where quality is still lacking.

5.2.1. There are ongoing concerns about the low quality of many behaviour support plans

Behaviour support looks to identify the drivers of behaviours of concerns and provide individualised plans intended to respond to and, over time reduce, instances of these behaviours. Identifying the underlying causes of behaviours of concern is especially important to improving quality of life and reducing and eliminating restrictive practices. In this context, it is essential to recognise that 'behaviours of concern' can be 'behaviours of protest' or be caused by undiagnosed pain or a response to environmental factors. Identifying and then removing or ameliorating these causes is essential.[2420]

Behaviour support aims to reduce and eliminate the use of restrictive practices. A BSP is a document prepared in consultation with the person with disability, their family, carers, and other support people that addresses the needs of the person identified as having complex behaviours of concern. There is a primary emphasis on upholding the rights of the person with disability by looking to support the person through evidence-informed, person-centred strategies reflected in a BSP. The BSP also provides context for the limited circumstances in which a regulated restrictive practice may be used on the pathway to elimination.

Good quality BSPs lead to better outcomes for participants, as they can result in reduced reliance on restrictive practices, improved stability of living arrangements, better engagement and performance at school, and greater connection to community.[2421] However, we have heard consistent concerns around the quality of BSPs for participants.

> *"The [current NDIS Quality and Safeguarding] Framework does not manage well the quality of behaviour support being provided, with self-assessment [by the behaviour support practitioner] being a key component and limited behaviour support plan review by the Commission." – Non-government organisation[2422]*

"There are very poor quality plans coming through with a 'cookie cutter approach.'"–
Community Living Options[2423]

In 2022, the NDIS Commission undertook a review of the quality of 2,744 BSPs submitted between 1 July 2020 and 31 December 2021. [2424] The review found that 80 per cent of BSPs were scored as 'underdeveloped' or 'weak' overall, and the national median score fell in the 'weak' range. While BSPs generally scored well in domains related to identifying and analysing behaviours of concern and developing reactive strategies to respond to their occurrence, they scored particularly poorly in domains related to building a participant's capacity to proactively prevent the behaviour from emerging. Key findings are summarised in Box 95.

Box 95: Overview of findings from the NDIS Commission's quality review of BSPs[2425]

- 80 per cent of BSPs fully addressed criteria relating to **identifying behaviours of concern**.
- 83 per cent of BSPs fully addressed the **predictors** of the identified behaviours.
- However, 81 per cent of plans **did not incorporate discussion of goals and objectives** for the plan.
- More than 50 per cent of plans had **no clear evidence of a plan to train implementing providers** in the interventions.
- More than two thirds (68 per cent) of BSPs were prepared **without consultation with the participant** who was the subject of the BSP.

These issues are longstanding in behaviour support, and stubbornly persist under the NDIS. The findings of the NDIS Commission's review mirror those of a state-wide audit of the quality of 139 BSPs conducted by researchers from the University of Queensland in 2018 (prior to transition to the NDIS), which found deficiencies in the same domains.[2426] Similarly, a 2010 study by researchers from Deakin University reported that in a review of 174 BSPs, most scored poorly on describing replacement or alternative behaviours (adequately described in 24 per cent of plans), teaching strategies (24 per cent), specifying reinforcers (6 per cent), goals and objectives (4 per cent) and communicating to all stakeholders (3 per cent).[2427]

Mirroring these findings about poor communication to all stakeholders, we have heard significant concerns that many BSPs are not being written in a way that supports their implementation. This concern has also been raised in relevant literature, where research has shown that BSPs can be longer and more technical in their language than is helpful for the implementing workforce.[2428]

Poor quality BSPs are difficult to implement and ineffective at reducing the occurrence of behaviours of concern. This puts at risk the safety, health and wellbeing of the participant and other people in the service environment (such as workers), including through the use of restrictive practices.

Many aspects of BSP quality are prescribed through the NDIS Quality Indicators, which describe the indicators that should be demonstrated in order for a provider to be deemed compliant with the NDIS Practice Standards. These indicators include having behaviour support plans that are evidence-informed and proactive, are developed in consultation with participants and implementing providers, and consider all relevant and appropriate information in their development.[2429]

With many BSPs not meeting the requirements in these indicators, especially on requirements such as consulting the participant and engaging implementing providers, we believe these requirements need to be elevated to greater prominence in regulation to bring their importance to the fore. This should be accompanied by greater compliance action against providers who are repeatedly non-compliant with their obligations (see Action 18.1).

5.2.2. The NDIS Commission monitors the quality of behaviour support practitioners and plans, but much more should be done to promote quality behaviour support planning

The NDIS Commission and state and territory authorities share responsibility for ensuring the quality of behaviour support plans (see Box 96). Other actors – including the NDIA, behaviour support practitioners and implementing providers – also have key roles to play.

Box 96: Roles and responsibilities for behavior support plan quality[2430]

The NDIS Quality and Safeguards Commission (NDIS Commission):

- Assesses the suitability of behaviour support practitioners to deliver specialist behavior assessments and planning, consistent with the Positive Behaviour Support Capability Framework and in line with the functions of the NDIS Commission under the NDIS Act.
- Receives BSPs containing restrictive practices that are lodged by providers.
- Monitors compliance with registration requirements, including requirements for providers to seek authorisation to use restrictive practices and develop a BSP, in line with the functions of the NDIS Commission under the NDIS Act.
- Provides guidance and policies on delivery of high quality BSPs and reductions in restrictive practices, in line with functions of the NDIS Commission under the NDIS Act.
- Encourages coordination between state and territory authorities on restrictive practice authorisation and monitoring.

State and territory authorities:

- Administer processes for authorising the use of restrictive practices, including reviewing BSPs (depending on state/territory rules).
- Provide guidance and policies on the delivery of restrictive practices and reductions in their use.

The National Disability Insurance Agency (NDIA):

- Provides plan funding for the development and implementation of quality BSPs.

Behaviour support practitioners:

- Secure approval from the NDIS Commission through an assessment of suitability against the Positive Behaviour Support Capability Framework.
- Develop BSPs in line with the expectations set out in the NDIS Restrictive Practices and Behaviour Support Rules, and NDIS Practice Standards and Quality Indicators.[2431]
- Undertake continuous professional development to build their skills and expertise to deliver improved outcomes for people with disability.

Implementing providers:

- Ensure the behaviour support practitioners they employ are developing BSPs in line with the expectations set out in the NDIS Restrictive Practices and Behaviour Support Rules, and NDIS Practice Standards and Quality Indicators.
- Implement quality behaviour support with participants, in accordance with a behaviour support plan.

The focus of BSP quality initiatives since establishment of the NDIS Commission has been on implementing a nationally consistent approach to the regulation of behaviour support practitioners, and providing general support to build the capability of practitioners through initiatives such as the Positive Behaviour Support Capability Framework.[2432]

The purpose of the Positive Behaviour Support Capability Framework is to define principles, values and capability domains for providers, embed a clear commitment to the reduction and elimination of restrictive practices, and outline expectations for supervision and continuing professional development for providers in a behaviour support context.[2433] We also note that some universities have developed courses and training for behaviour support practitioners, such as Flinders University and Monash University, in line with the requirements under the Positive Behaviour Support Capability Framework.[2434]

Now that these functions are established, we see a need for the new National Disability Supports Quality and Safeguards Commission to focus its attention on key systemic quality issues, including those we identified in Section 5.2.1:

- Inconsistent embedding of proactive, preventative strategies in BSPs (for example, describing replacement or alternative behaviours, teaching strategies, specifying reinforcers, and identifying goals and objectives).
- Insufficient communication from behaviour support practitioners to all stakeholders who will be impacted by the strategies in the BSP, most critically the person to whom the BSP relates.
- The suitability of language and content in BSPs for those who need to implement the plan.

Based on our engagement with behaviour support practitioners, we consider that regulation is only part of the solution. A stronger focus on driving quality improvement across the market (as discussed in Section 4 and Recommendation 12) should include actions to support quality improvement in behaviour support planning. While there is already a process in place for practitioners to demonstrate their suitability to deliver these supports, we have identified that more can be done to improve the overall quality of practitioners and the behaviour support assessments and plans being developed.

> *"[There is an]... over focus on regulation which has not resulted in quality or person and family centred being put at the forefront [of behaviour support planning]. For example, with the requirement to lodge interim plans within 1 month, irrespective of the amount of time, supports and funding it can be challenging to engage the participant or their family to meaningfully in this process. The regulations do not differentiate around the level of risk related to the restrictive practice, the implementers or the practice, the time needed for meaningful engagement for that participant or other factors." – Non-government organisation* [2435]

To be true to our international obligations and to give effect to the statutory functions outlined in the NDIS Act, the new National Disability Supports Quality and Safeguards Commission must demonstrate strong leadership on these issues, with more intensive focus on its responsibility for researching and promoting best practice models targeted to longstanding and emerging systemic issues.

As noted in Action 12.1, we consider developing better strategies to improve the quality of behaviour support plans and drive the reduction and elimination of restrictive practices should be an immediate focus for the recommended Deputy Commissioner for Quality and supporting quality function. This should build on initiatives such as the recently released 'Deciding with Support' toolkit, developed by Flinders University in conjunction with the Council for Intellectual Disability and University of New South Wales, using NDIS Commission grant funding. This toolkit, which was co-designed and tested by people with disability, contains practical resources to empower people with disability to be actively involved in the development of their behaviour support plans and is free to anyone involved in positive behaviour support, including people with disability, their supports, providers and behaviour support practitioners. [2436]

5.2.3. Funding arrangements must enable high-quality behaviour support planning and implementation, supported by timely identification of the need for behaviour support

In addition to concerns about regulation, we have heard that there is a high degree of variability in terms of funding allocated in participants' plans for behaviour support – with inadequate funding contributing to poorer quality planning and implementation, and ultimately a lack of progress in reducing and eliminating restrictive practices. Variability in funding logically translates to variability in the time available to a behaviour support practitioner to work through a quality process, including supporting implementation. [2437]

"Funding for Behaviour Support Plan development and reviews is seldom sufficient in any person's plan. This may be due to inadequate assessment and planning, but it impedes capacity for Behaviour Support Planning and therefore reduces the prospect of positive outcomes for the person." – Non-government organisation[2438]

The current funding approach for the development and implementation of BSPs involves participants being allocated funding as part of their NDIS plans. However, the current planning process does not always sufficiently identify a need for behaviour support planning, and even when need is identified, may not always provide sufficient funding to both develop and then implement the plan.[2439] It is also not responsive to urgent and unexpected safeguarding issues. Implementing providers have raised concerns that the process of developing a BSP is outside of their control, despite having a regulatory obligation to have a BSP in place. As a result, URPs may be employed by providers while waiting for a participant to receive behaviour support funding in their plan, or for a behaviour support practitioner to be available to work with the participant (particularly in thin markets).[2440] Similarly, if funding is not provided in a participant's plan in the first place, a plan review is needed to access this funding, creating further delays and additional risks of URP use.

Concerns were also raised with us that there is insufficient funding available to train staff on how to properly implement the BSP despite this being a requirement under the NDIS Practice Standards and Quality Indicators, or that less restrictive options require greater resources than is funded in a participant's plan.[2441]

"Strategies and interventions that can reduce and prevent the need for restrictive practices, are frequently overlooked at the planning stage, feeding into the cycle of escalated restrictive practices... There is a strong evidence-base and policy case for using support worker training, environmental modification and sensory modulation strategies to reduce restrictive practice. However, there are barriers to people with psychosocial disabilities gaining access to these interventions, including unclear guidelines; and knowledge and understanding of the NDIS planning workforce." – Advocate[2442]

The work needed to support a person to put in place behavioural change strategies, and to build the capacity of the people around them to implement these strategies, is intensive. Trust and connections must be built in order for quality outcomes to be realised for people with challenging behaviours.

"With his extraordinary anxieties, building trust with a few highly attuned and trusted communication partners provides [our son] with a source of security and is vital to his wellbeing. People who can't 'read' [him] expertly fail very quickly in trying to support him." – Carer[2443]

"... there often appears to be a focus on the development of behaviour support plans, but less focus on the implementation, monitoring, and review of these plans. For example, we are aware of numerous situations where staff working with NDIS

participants do not know about the participants' behaviour support plans, where behaviour support plans are not being implemented properly, or where plans that appear not to be effective remain in place." – Public Advocates and Guardians[2444]

Resource intensity may also be higher when deploying the least restrictive approach to managing behaviours of concern, however the least restrictive approach is a key principle of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector.[2445]

"[Participant Y] began to have some issues with swallowing and choking and was diagnosed with dysphagia. Her dysphagia management plan requires that the Participant Y has close 1:1 supervision at all mealtimes... her funding does not allow for 1:1 supports... After choking incidents when Participant Y independently accessed food and drink, for safeguarding reasons we took the decision to restrict her access to food and drink by locking it away... With appropriate funding for support – which in these circumstances would be 1:1 – a restrictive practice would not be necessary." – Provider[2446]

Requirements for behaviour support planning and implementation must be identified early and adequately funded. Our recommended risk assessment and safeguard building process (see Action 16.2) as part of needs assessment processes (see Action 3.4) provides an opportunity to identify the need for a BSP. Navigators should then provide an avenue to respond to any need identified by supporting participants to access good quality behaviour support. Navigators would also be able to identify and respond to any need for a BSP that may emerge after initial needs and risk assessment processes.

Inadequate funding across BSP development and implementation processes will lead to poor outcomes, and ultimately a lack of progress against our key objective of reducing and eliminating restrictive practices. As described above, the existing model of funding is problematic – it does not appear to provide timely or adequate funding to respond to an urgent safeguarding issue; it takes the process of developing a BSP out of the control of implementing providers despite these providers having regulatory obligations regarding the development and implementation of a BSP (whether or not it has been funded in the participant's plan); and it gives rise to the perverse situation of participants effectively giving approval for their provider to breach their own human rights by exercising choice and control over the use of their budget.

This issue becomes more pertinent in the context of our recommendation regarding improved flexibility in how individual budgets can be spent (see Action 3.5). Ensuring there is sufficient funding available to support quality behaviour support processes where necessary, while not impeding this key change, requires a considered approach. We are of the view that consideration must be given to an alternative model for funding providers to develop and implement high quality BSPs, potentially providing this funding outside individual budgets.

Possible options could include direct commissioning, panel arrangements, voucher mechanisms, or incorporating costs associated with developing and implementing behaviour support plans into

relevant price caps (with regard given to how price caps may be differentiated to account for the costs of delivering supports to participants with more complex needs – see Action 11.1). Consideration of these options must involve people with disability, their families and representative organisations, the NDIA and the new National Disability Supports Quality and Safeguards Commission.

While further consideration and consultation is required, we believe there are several key principles that should guide the approach to funding the development and implementation of high quality BSPs going forward. In particular, the funding approach should:

- Identify the need for behaviour support as early as possible to ensure participants get timely access to quality behaviour support (including through the risk assessment and safeguard building process – see Action 16.2).
- Enable providers to access funding to have a BSP developed in a timely manner in order to meet their regulatory obligations.
- Take into account the costs of ongoing implementation of behaviour support, including accounting for any staff training requirements, and recognising that the least restrictive approach to managing behaviours of concern may be more costly.
- Provide avenues for any risks arising from inadequate funding of behaviour support to be identified, raised and addressed directly by the new National Disability Supports Quality and Safeguards Commission, as well as the NDIA.

5.2.4.   Action & Implementation Details

Action 18.2: The new National Disability Supports Quality and Safeguards Commission, working with other agencies as relevant, should work with behaviour support practitioners and providers to urgently improve the quality of behaviour support plans, enhance quality of life for participants and eliminate poor provider practices.

Immediate priorities should include practice leadership, capability uplift for behaviour support practitioners and ensuring that regulatory and market settings support best practice. There should be a clear action plan, which brings together specific initiatives and considerations for quality improvements, with appropriate timeframes for action. Further consideration should also be given to alternative models for funding providers to develop and implement behaviour support plans to ensure timely access and adequate funding for quality behaviour support, including use of the risk assessment and safeguard building process (see Action 16.2) to identify the need for a Behaviour Support Plan.

Implementation detail:

- The new National Disability Supports Quality and Safeguards Commission should develop an action plan to drive improvements in the capability and supply of behaviour support practitioners to develop high quality behaviour support plans. This action plan should

build on work already completed and include further actions to drive an uplift in capabilities. The action plan should have the following features:

- Be developed through strong consultation with key stakeholders, including people with disability who have experience of behaviour support and restrictive practices, disability rights advocates, behaviour support practitioners and implementing providers. This should include representation of people facing intersectional discrimination and inequality (including First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities).

- Drive the new National Disability Supports Quality and Safeguards Commission to adopt a leadership role to ensure that settings across the system (including regulatory settings, funding and pricing arrangements) support high quality behavior support planning and implementation, working with other parts of government as needed.

- Include specific actions that will support increases in the supply and capability of good quality behaviour support practitioners, including training and resources to support their knowledge and understanding of best practice behavior support (for example, case studies detailing practical examples of best practice behaviour support that does not use restrictive practices).

- Include specific actions that will improve the volume and quality of feedback provided by the new National Disability Supports Quality and Safeguards Commission to behaviour support practitioners about the behavior support plans they produce, and to state and territory authorities about the restrictive practices they authorise. This should include feedback on performance at both the level of the individual practitioner and the system, as well as sharing data and insights arising from the review of behaviour support plans.

- Include specific actions to strengthen behaviour support practitioners' focus on undertaking behaviour support planning in ways aligned with good practice, such as ensuring sufficient consultation has occurred with all parties impacted by the behaviour support plan (in particular, with participants). This may include elevating these expectations from the Quality Indicators into the Practice Standards.

• The NDIA, working with the new National Disability Supports Quality and Safeguards Commission, should give consideration (as part of allowing more flexibility in how participants can spend their funding package – see Action 3.5) to an alternative model for funding providers to develop and implement behaviour support plans. This could include direct commissioning, panel arrangements, voucher mechanisms or incorporating costs into relevant price caps. This should ensure timely access to behaviour support planning and appropriate funding for both planning and implementation.

- A new approach must be supported by timely identification of the need for a BSP, including through the risk assessment and safeguard building process (see Action 16.2).

- Any new approach must be developed through strong engagement with key stakeholders, including people with disability who have experience of behaviour support and restrictive practices, disability rights advocates, behaviour support practitioners and implementing providers.

5.3. Implementing providers have a critical role to play in reducing and eliminating the use of restrictive practices

Improving the quality of BSPs is only part of the puzzle in reducing and eliminating the use of restrictive practices. The providers and workers who implement these plans have a critical role to play in ensuring they lead to the outcomes sought. We have observed that implementing providers continue to use restrictive practices for a range of reasons.

Cultural change underpinned by education and capacity-building is needed, and regulatory and market arrangements must support this. Critically, people with lived experience of restrictive practices must be heard.

5.3.1. Implementing providers continue to use restrictive practices for a range of reasons, and need more support to shift their approach

Participants, families and carers have told us that they perceive a continued overreliance on restrictive practices by NDIS providers and workers that leaves people with disability at risk of harm, and can undermine the ability for both participants and workers to recognise and respond to violence by normalising rights violations.[2447] We have heard particular concerns around the degree to which restrictive practices have become entrenched in congregate care settings, such as group homes.[2448]

> "… the use of restrictive practices, including the use of chemical restraints, physical barriers, physical restraints, and environmental restraints, has occurred heavily in the SILs. Some residents of the SILs reported that they were tied to a chair to restrict their freedom of movement. Also, fridges and doors were locked to restrict them from accessing food and free movement." – Dr Piers Gooding et al. (University of Melbourne)[2449]

There is a perception that providers often use restrictive practices out of convenience, because it is what they have always done, or under the guise of participant or staff safety.[2450]

> "While there is nothing wrong with the idea of being safe, if approaches to safety are not undertaken in the context of good life chances, those safety measures can serve to

> *hold the person back, or even actively diminish their chances of a good life. This happens a lot for people who are labelled as having 'behaviours of concern' resulting in 'restrictive practices' being a feature of their support arrangements." – JFA Purple Orange[2451]*

One area of particular concern raised with us is reliance on the use of physical restraint. High-risk forms of physical restraint are prohibited practices (see Section 5.1.5). While reported levels of physical restraint usage in NDIS services are lower than other types of restrictive practice, people with disability continue to face high levels of practices in settings where their supports may be provided, such as in health settings.[2452] More should be done to support providers to consider and implement alternative strategies, and to help people with disability and their supporters to raise concerns about harmful physical restraints.

Implementing providers have also raised a number of issues that they see as contributing to their continued use of restrictive practices against participants. Issues with funding and timeliness of access to behaviour support practitioners (see Section 5.2.3) were commonly raised. Several providers also raised concerns that the quality of behaviour support practitioners and BSPs is not sufficient to offer implementing providers the support they need to reduce their reliance on restrictive practices.[2453] These issues are compounded by plans that are not written in a way that helps providers to implement them, being lengthy and using overly technical language.[2454]

Submissions from providers left the impression that greater focus was being afforded to the authorisation of and reporting on restrictive practices, as opposed to reduction and elimination.

We have heard a number of ideas about what providers could do to turn the tide – including greater access to sensory modulation supports, supporting greater freedom of self-expression, and optimising the participant's environment.[2455] We have heard about the important role that models and frameworks such as Social Role Valorisation and Active Support can play in supporting the reduction and elimination of restrictive practices when employed by NDIS providers.[2456] Many have stressed the importance of improved training of support workers in achieving the goal of reducing and eliminating restrictive practices.[2457]

> *"As established in the Review's recent workforce report, 1 in 4 NDIS workers received less [than] one day of training in the past year and only 1 in 3 receive the supervision they need (with the rate dropping to 1 in 4 for casual workers)... the Commission currently provides eLearning units for NDIS workers. However, these are generalist units and do not provide detailed information on complex issues including abuse, neglect and restrictive practices." – MS Australia[2458]*

Providers need the system to support them to do better. They need funding approaches to reflect the intensity and types of support participants will need to live their lives with the least restriction possible (see Section 5.2.3 and Action 18.2). They need clear, consistent direction that reinforces the important message of reduction and elimination. They need government processes and regulatory and market settings to support them to deliver this (see Actions 18.1 and 18.2).[2459] Finally, they need information, education, training and data focused on helping them understand

and implement approaches that ensure the participants they service enjoy a good quality of life with the least restriction possible, and track their performance benchmarked against their industry.[2460]

Training and resources must focus on practical steps that providers and workers can adopt in their practice to reduce reliance on restrictive practices. Because each person and situation is different, resources must consider a very broad range of scenarios and focus on building foundational skills in, and commitment towards, providing good quality of life for people with disability. Training needs to build a realistic pathway towards reduction and elimination of restrictive practices that recognises the reality that where a person is at risk of harming themselves or others, restrictive practices may need to be used – while emphasising that in a quality of life framework, the least restrictive option should always be used, and only ever as a last resort in response to serious and imminent risk.

A new approach is needed to ensure all parts of the system have a common understanding of the goal of reducing and eliminating restrictive practices and how to get there. It is important that this is not just the domain of governments and providers – people with disability who have experience of restrictive practices must have a seat at the table.

> *"Until restrictive practices are regulated by agencies informed by people with lived experience of restrictive practices, they will continue to be applied inappropriately and continue to cause harm... the entire system has been designed and implemented by people who do not need the safeguards it is intended to provide." – Villamanta Disability Rights Legal Service[2461]*

5.3.2.   Providers must embrace the ambition of improving the quality of behaviour support and enhancing the quality of life of participants

The new National Disability Supports Quality and Safeguards Commission should adopt a quality improvement agenda that firstly brings all providers up to a minimum standard of meeting regulatory requirements, and then moves beyond this to work towards driving greater quality of life for participants. It must focus on challenging the use of restrictive practices (even when used with authorisation) and encouraging providers to implement effective alternatives through a clear commitment to ensuring the best quality of life possible for the people with disability that they serve.

We recognise the significant efforts required by behaviour support practitioners, providers and workers to move away from historical practices of restriction in disability services. However, we strongly believe providers must take responsibility for the reduction and elimination of restrictive practices. A strong message has emerged from the community, supported by research, of the important role that organisational culture plays in achieving the important aim of reducing and eliminating restrictive practices.[2462]

> *"Lancaster Consulting Australia attributed the use of restrictive practices to a 'lack of fundamental respect for the human rights' of people with disability. It told us that if a*

service has a 'culture of bullying and intimidation', staff will 'often use many' restrictive practices. Restrictive practices may also be used where staff become 'task focused' rather than 'person centred'." – Disability Royal Commission Overview of responses to its Restrictive Practices Issues Paper[2463]

Organisational cultures must shift to drive improved quality of life for the people that use their services. These cultural shifts must be supported and reinforced by:

- strong and consistent focus and messaging from organisational leadership on the importance of reduction and elimination of restrictive practices;
- systems through which organisations can monitor and review their use of restrictive practices; and
- support for workers to implement good quality behaviour support that increases the person's choice and control over the own lives, working with families, supporters and behaviour support practitioners to reduce the use of restrictive practices and only ever use the least restrictive option possible.

"In studies that provided details about the nature of the 'intervention' that took place to produce a positive outcome, what appears to have changed is the quality of the environment and service being provided to the person with disability." – Spivakovsky, Steele and Wadiwel (2023)[2464]

Through our engagements with implementing providers, perspectives around barriers introduced by current settings and regulatory burden have dominated, including inconsistencies in authorisation processes, differences in definitions, and high volumes of reporting.[2465] Often, these are framed as frustrations for implementing providers and not as risks to the safety, health, wellbeing, rights and dignity of participants.

We acknowledge these challenges, and our recommendations seek to improve these settings. However, this will not be enough in and of itself. It is critical that all providers take responsibility for building a positive rights-based culture that is focused on improving quality of life for people with disability, and for ensuring that they have the capability and strategies needed to reduce and eliminate the use of restrictive practices.

Ongoing leadership and support from the new National Disability Supports Quality and Safeguards Commission and state and territory authorities should support this. Similarly, the NDIA has a role to play in facilitating this through funding approaches for supports such as 24/7 living supports, Navigators and Shared Support Facilitators, particularly to address inappropriate living arrangements that result in in prolonged use of restrictive practices (see Recommendations 4 and 8). However, ultimately, efforts must be grounded within provider organisations themselves to achieve the substantial change needed to reduce and eliminate restrictive practices.

5.3.3. Action & Implementation Details

Action 18.3: The new National Disability Supports Quality and Safeguards Commission, working with state and territory agencies, should better support providers to deliver on their role in reducing and eliminating restrictive practices

All agencies should work with providers to build a positive rights-based culture that is focused on improving quality of life for participants. This should be achieved through coordinated education and support from the regulatory system to build the necessary culture, governance and leadership in providers, strategic leadership by providers, training for staff, and high-quality behaviour support for participants that will reduce and eliminate restrictive practices.

Implementation detail:

- The new National Disability Supports Quality and Safeguards Commission and state and territory authorities (working closely with relevant experts in education and training for sector development) should develop and provide educational activities to build the necessary culture, governance and leadership in providers, to support them to embed the organisational culture and practices needed to drive reduction and elimination of restrictive practices.

    - These educational activities should be supported by action to give providers greater access to data and metrics regarding the use of restrictive practices in their own and other comparable services, to support providers to benchmark themselves and improve efforts to reduce and eliminate the use of restrictive practices.

- The new National Disability Supports Quality and Safeguards Commission should establish a community of practice expert group involving people with disability with experience of behaviour support and restrictive practices, disability rights advocates, behaviour support practitioners, implementing providers and clinical experts to share information and strategies to improve behaviour support implementation and reduce and eliminate the use of restrictive practices.

    - This should include specific representation of people facing intersectional discrimination and inequality (including First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities).

    - The community of practice expert group should give priority attention to considering strategies to reduce and eliminate the use of physical restraint.

- The new National Disability Supports Quality and Safeguards Commission (led by the new quality function, see Action 12.1) should develop resources for implementing providers that provide them with guidance on actions they can explore to reduce the use of restrictive practices in their services. This should include:

- Development of evidence-based, person-centred models that providers can implement which focus on the improvement of the person's quality of life and reduce the occurrence of behaviours of concern and the use of restrictive practices.

- Development of strategies and practical examples that providers can implement to reduce and eliminate the use of physical restraint (giving consideration to the work of the community of practice expert group described above).

- Development of case examples to inform provider understanding of the specific circumstances in which an environmental restraint may increase the person's quality of life (for example, if an environmental restraint was the least restrictive alternative and led to a measurable improvement in the person's quality of life).

- The new National Disability Supports Quality and Safeguards Commission and the Department of Social Services should consider the appropriate level of investment in the workforce responsible for implementing behaviour support and restrictive practices to ensure that best practice solutions can be delivered for participants.

  - This should include developing training resources to strengthen the capability of workers implementing behaviour support plans, building on the NDIS Workforce Capability Framework.

6. Effective quality and safeguarding institutions and architecture across the full disability ecosystem

- Having the right supporting architecture and institutions to drive quality and safeguarding is equally as important as having the right tools and approaches. The development of the NDIS Quality and Safeguarding Framework in 2016 set the scene for how quality and safeguarding would be assured in the scheme, including through coordinated efforts of a new NDIS Quality and Safeguards Commission (NDIS Commission) to oversee national regulatory arrangements, supported by state and territory government agencies. Transition to these arrangements was staged from 2018, concluding in July 2023. These first steps represent significant achievements towards assuring a consistent experience of quality, safe supports and services for participants.

- However, to date, many challenges experienced in quality and safeguarding highlight a lack of clear strategy, coordination and accountability across all parts of the system that have roles to play. Efforts by regulators are not being approached in the strategic, coordinated way that a scheme as large as the NDIS – as well as the wider disability support ecosystem – warrants. There is also confusion about who is responsible for what, and a lack of information sharing to support the system to deliver good outcomes.

- We see opportunities to drive more consistency and coordination in regulation across the disability support ecosystem, as well as with adjacent markets such as aged care. Doing so will

ensure consistent, effective protections for all people with care and support needs, while also driving efficiencies for governments and providers. These efforts should begin with expanding the coverage of the NDIS Commission to be the new National Disability Supports Quality and Safeguards Commission, with responsibility for the regulation of all Australian Government funded disability supports.

- While it has delivered a range of achievements to date, it is clear the NDIS Commission was not set up for success. There are opportunities to improve its capability and effectiveness, noting its central role as the NDIS regulator and the added complexities and challenges that will arise from expanding its coverage.

- Getting the supporting architecture and institutions of the quality and safeguarding system right is an absolute priority, and critical to the successful implementation of other recommendations we are making. It is imperative that all parts of government are accountable, well-coordinated and operating effectively – supported by the right tools, capabilities and information – in order to deliver on these ambitions.

Recommendation 19: Embed effective quality and safeguarding institutions and architecture across the disability support ecosystem

📃 Legislative change required

- Action 19.1: The <u>Disability Reform Ministerial Council</u> should agree a Disability Supports Quality and Safeguarding Framework.
- 📃 Action 19.2: <u>All Australian governments</u> should prioritise greater collaboration, consistency and timely exchange of data and information to ensure effective quality and safeguarding, including expanding the coverage of the NDIS Quality and Safeguards Commission to become the National Disability Supports Quality and Safeguards Commission.
- 📃 Action 19.3: The <u>Australian Government</u> should ensure the new National Disability Supports Quality and Safeguards Commission has the resources, powers and approach to proactively and effectively regulate the disability supports market.

6.1. Quality and safeguarding in disability supports is not pursued in a strategic, coordinated or consistent way

The NDIS is a large and complex system, with over 610,000 participants supported by over 16,000 registered providers, over 154,000 unregistered providers and over 325,000 workers.[2466] A range of people and organisations have both formal and informal roles and responsibilities to support a quality, safe experience of supports for people with disability. Excellent coordination and consistency are essential to ensuring the system is delivering good outcomes for participants.

However, to date, many of the challenges experienced in quality and safeguarding suggest the system is not coordinated, nor consistent. Regulation is not being approached in the strategic, coordinated and consistent way that people with disability deserve, and that a scheme as large as

the NDIS – as well as the wider disability support ecosystem – warrants. There is confusion about who is responsible for what, and a lack of information sharing to support the system to deliver good outcomes. There are also opportunities to drive more consistency in regulation across the NDIS, other disability supports, and adjacent markets.

6.1.1.   Roles and responsibilities for quality and safeguarding are fragmented and unclear

The 2016 NDIS Quality and Safeguarding Framework (the Framework) set a vision for the activities of different groups with both formal and informal quality and safeguarding roles and responsibilities and how they would be coordinated under an overarching architecture and strategic approach.[2467] This included the roles of formal regulators such as the NDIS Commission, providers and workers delivering supports in the market, and the natural supports and safeguards available to participants. These roles are outlined in Box 97.

Box 97: Roles and responsibilities under the 2016 NDIS Quality and Safeguarding Framework

- **Individuals (participants)** self-advocate about how supports are delivered and raise concerns about supports and services.
- **Natural supports** such as families, carers and community support participants to engage with NDIS supports, and advocate for quality and safety for participants when required.
- **Providers, intermediaries and workers** deliver safe and quality supports to participants (both direct supports and intermediary services). This includes engaging with participants about what supports are delivered and how, and raising and acting on concerns about the quality and safety of supports.
- **The Department of Social Services (DSS)** develops and advises on policy and legislative frameworks for the NDIS (including quality and safeguarding policy), and funds advocacy services and other programs.
- **The NDIS Quality and Safeguards Commission (NDIS Commission)** regulates the provider and worker market to reduce risk to participants, drive quality in the delivery of supports and exercise market oversight; responds to and investigates complaints and incidents; regulates the use of restrictive practices; and promotes positive behavior support strategies to reduce and eliminate restrictive practices. In order to deliver its regulatory functions, the NDIS Commission also has a role in directly supporting participants to uphold their rights to safe and quality supports.
- **The National Disability Insurance Agency (NDIA)** assesses risks to participants throughout the NDIS planning pathway; ensures the quality of plans and reasonable and necessary funding for supports and services (including to mitigate risk); and supports informed decision-making and capacity development of participants. The NDIA also plays a role in regulating for, or otherwise upholding, quality and safeguards through the NDIS Pricing Arrangements and Price Limits (which apply to Agency-managed and plan-

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managed participants), and sets requirements and expectations for the delivery of some supports.[2468]

- **State and territory governments** implement worker screening arrangements; authorise restrictive practices; manage guardianship arrangements; manage Community Visitor Schemes (where available); ensure quality and safeguards in the delivery and regulation of mainstream services (such as hospitals and schools); and operate some protective and corrective arrangements (such as emergency services, police, and family services). State and territories also have a role to play in the regulation of state and territory funded disability supports outside of the NDIS.

However, strategy, responsibilities and coordination have not eventuated in the way the Framework envisaged they would. We identified a range of challenges with the implementation of the Framework in our 'NDIS Quality and Safeguarding Framework Issues Paper' published in April 2023,[2469] including:

- The Framework was developed to cover the period of transition to the full NDIS and therefore is out of date and does not reflect changes that have developed in the scheme and market.
- While many parts of the Framework have been operationalised, some parts have not been implemented as expected or at all.
- The Framework lacks clarity about the roles of different parties in the quality and safeguarding system and how they should work together, including other systems of support.
- The balance of different measures envisaged by the Framework – a combination of developmental, preventative and corrective measures, as well as a focus on both safety and quality – has not eventuated, with more focus on reactive responses when things go wrong instead of proactively trying to prevent things from going wrong.

Of particular importance, there is a distinct lack of clarity about the overarching strategy, who is responsible for ensuring participants are supported and safe, and how these different players should work together. Participants and their supporters have told us they find navigating the quality and safeguarding system to be unintuitive and confusing, particularly with regard to the split of responsibilities between the NDIA and NDIS Commission.[2470]

> *"The current complex landscape is fragmented and often inaccessible and ineffective for people with disability seeking remedies, recognition or resolution of their complaints or negative experiences with disability supports. The burden of this complexity falls on people with disability, their families and supporters..."* – Disability Advocacy Network Australia [2471]

> *"The Framework provides some guidance on the different roles and responsibilities between the NDIS Commission and the NDIA; however, it is not clear how the work of one agency influences or guides the work of the other and how this is coordinated*

beyond responding to individual circumstances. For example, decisions made by the NDIS Commission to introduce new Practice Standards are likely to require adjustments in the way that participant plans are developed or structured, in addition to the cost to providers of implementing these standards." – National Disability Services[2472]

The impact of this is particularly felt when issues arise and participants have the least capacity to navigate the system. For example, we have heard many stories of participants who have tried to raise concerns around providers' practices who feel they have been bounced around between the NDIA, NDIS Commission and their state or territory consumer protection agency trying to seek resolution.[2473]

We have observed that the Framework describes individual actions, sometimes ascribed to certain parties, but does not identify how these actions are to be coordinated and how parties are to be held accountable for delivering these actions. A key example of this is the absence from the implementation of the Framework of developmental measures targeted to participants, despite the Framework placing clear emphasis on their importance. No party is clearly responsible for ensuring the measures within the Framework are implemented, coordinated, reviewed and adjusted.

While the underlying principles of the Framework may be used to guide individual agencies' activities, there is no coordination to look at how these individual actions cumulatively support the goals of the Framework and how different parties experience the quality and safeguarding system. This means there is a lack of long-term, whole of scheme approaches to NDIS quality and safeguarding arrangements, and they are therefore experienced as fragmented actions by individual parties rather than holistic support, which was not the intention of the Framework's design.

"… the NDIS has many moving parts, with many roles. This complexity may lead to an end point where there is nobody that has… responsibility to make sure that things are going well overall for the individual." – Robertson Review [2474]

We have also observed that the Framework takes too narrow a view, focusing on quality and safeguarding for NDIS supports but not the broader ecosystem of supports for people with disability – which has resulted in quality and safeguarding in the NDIS being considered in isolation. Many participants, families and carers use other disability and care and support services outside of the NDIS (for example, through other disability supports and education, justice and health and community care programs) but not enough is done to ensure they have a consistent experience of quality and safeguarding. Many government agencies with formal roles in the Framework also have roles and responsibilities beyond the NDIS – for example, disability agencies, Community Visitor Schemes and Public Advocates and Public Guardians – but there is a lack of connection to their broader roles and limited efforts to ensure the NDIS works in coordination with this broader system.

Participants' interests are not served by this complexity, and it hinders coordination. It is essential that governments work in a coordinated, collaborative and consistent way to support good quality

and safeguarding outcomes for people with disability accessing supports across the whole of the disability support ecosystem. Given we are recommending a major investment in foundational supports (see Recommendation 1), relying on a narrow NDIS Quality and Safeguarding Framework – focused only on NDIS supports – will be even less appropriate in the future.

6.1.2. Information is not being shared sufficiently to support the system to deliver outcomes for people with disability

The spread of roles and responsibilities across the system means that open and timely sharing of information is vital to ensuring its effectiveness. Current information sharing arrangements are a clear pain point in the system, impeding better coordination and proactive action to support a safe, quality experience for participants. Better information sharing is essential to improve the responsiveness of the system to the needs of people with disability. Box 98 illustrates some of the ways in which information could be better shared to facilitate more effective regulation and safeguarding, including in connection with other recommendations of this Review.

Deficiencies in current data and information sharing arrangements mean there is no joined-up, system-wide view of understanding risk and safeguarding for individual participants, with different parts of the system holding different information about participants and therefore only having a piecemeal view. As a result, the regulatory and safeguarding system is not as effective as it should be and those who should intervene to prevent harm are not able to identify issues and trigger responses.

Challenges in current information sharing arrangements also manifest as ineffective or inefficient operation of the regulatory system more broadly. For example, duplicative requirements to report on the use of restrictive practices to both the NDIS Commission and the relevant state or territory authority add burdens for providers, and reflect a lack of collaboration and coordination in areas of shared regulatory responsibility (see Section 5.1.2).

We have observed, on the one hand, that people with disability want their personal data and information shared only for the right reasons in line with key privacy principles such as the need to know; and, on the other hand, that some government agencies may be taking an excessively cautious approach to sharing information that is compromising effective safeguarding. We believe a path can be found that respects privacy considerations and that leads to improved data and information sharing, allowing the system to be much more responsive to risks.

We are of the view that the lack of clarity regarding roles and responsibilities outlined in Section 6.1.1 contributes the lack of information sharing and an insufficiently collaborative culture between different parts and levels of government.

Both the Robertson Review and the Joint Standing Committee on the NDIS inquiry into the NDIS Commission highlighted opportunities for change to improve the flow of information across the system.[2475] While the Australian Government's response to the Joint Standing Committee's inquiry indicated that the legislative changes made following the Robertson Review through the National Disability Insurance Scheme Amendment (Improving Supports for At Risk Participants) Act 2021

would address these matters, including by prescribing bodies or persons with whom the NDIS Commissioner may share information for the purposes of the National Disability Insurance Scheme Act 2013 (NDIS Act), this framework is yet to be operationalised as envisaged.[2476] This must be resolved as a priority. In addition to the legislative framework, a coordinated effort across agencies to improve culture, capability, systems and processes for timely two-way information and data exchanges between all parts of government – recognising the different types of information relevant to the roles and responsibilities of the parties involved – is critical.

Box 98: Possible information flows in the regulatory and safeguarding system

We have observed a range of types of information that should be better shared across the NDIS system to support quality and safeguarding efforts.

- Information shared between the new National Disability Supports Quality and Safeguards Commission and the NDIA, as well as state and territory agencies, to provide **risk flags to identify where participants may be at high risk of harm**, such as indicators of participants receiving high-risk supports and/or receiving supports in formal and closed settings. This information could prompt check-ins and the provision of additional support as part of the risk assessment and safeguard building process (see Actions 16.2 and 16.3).
- Information provided by a participant to another government agency that would **indicate their circumstances have changed** – for example, that they have moved house or have applied to Services Australia to receive a crisis payment following the breakdown of a relationship. This information could create a flag in the system for check-ins with participants by navigators or NDIS agencies (see Action 16.2).
- Information held by the new National Disability Supports Quality and Safeguards Commission that would support third-party auditors to understand the types of **issues that have been observed** in relation to an individual provider's operations in the market or systemic issues being observed across the market, to inform their audit processes (see Action 12.2).
- Information gathered by third-party auditors that would support the new National Disability Supports Quality and Safeguards Commission to better understand which areas of the Practice Standards providers are most frequently **needing support to come into compliance** with at the audit stage, to inform the development of capacity-building initiatives (see Action 12.2).
- Information and referrals from Australian Government and state and territory agencies that would support Community Visitor Schemes to know **when people with disability in their respective state or territory would benefit from outreach**, and to **target their outreach** activities to those most in need, (see Action 16.3).
- Information from Community Visitor Schemes that would support the new National Disability Supports Quality and Safeguards Commission's efforts to **regulate the market**.

This could include a report of concerns about misconduct or abuse for the Commission to investigate.

- Information from Australian Government agencies that would support state and territory child protection and adult safeguarding agencies to **monitor and support people with disability at risk** in their communities. This could include sharing information about systemic risks and issues identified by regulators, or referrals of individuals needing support from child protection and adult safeguarding agencies.

- Information from state and territory child protection and adult safeguarding agencies to the new National Disability Supports Quality and Safeguards Commission and the NDIA to **ensure they are providing adequate and appropriate support** to people with disability engaged with these agencies.

- Information from the new National Disability Supports Quality and Safeguards Commission to state and territory authorities regarding the **reporting of unauthorised restrictive practices, behaviour support plans and reporting against those plans** to support the role of state and territories in authorising restrictive practices (see Action 18.1).

6.1.3. Different regulation is being applied to the same problems, and often the same people

We have observed a distinct lack of consistency and coordination in the approach to quality and safeguarding both within the NDIS, and between the scheme and other disability supports and adjacent care and support programs.

Not all NDIS supports and services are regulated in the same way or by the same regulator. For example, both the NDIA and the NDIS Commission set rules for providers and workers. We have identified a number of rules set through the NDIA Pricing Arrangements and Price Limits, as well as NDIA operational guidance for specialist disability accommodation, support coordination and plan management, which set out provider expectations that are separate from NDIS Commission requirements but still relate to quality and safety.[2477]

Adding further complexity, not all NDIS providers are regulated by the NDIS Commission – for example, NDIS Commission regulation does not apply to directly commissioned supports such as Local Area Coordinators (which are contractors of the NDIA) despite having direct service relationships with people with disability, something which has been raised as a concern in previously inquiries.[2478]

We have also observed a lack of consistency, coordination and integration in the approach to quality and safeguarding between the NDIS, the broader disability support ecosystem and other care and support systems (such as aged care, veterans' care and child care) that participants, families and carers commonly engage with. This leads to significant confusion, frustration, and ultimately poor outcomes for participants, families and carers.

For example, similar services for people with care and support needs are available through a range of Australian Government and state and territory government programs, yet there are separate and overlapping regulatory frameworks. At the centre of these frameworks is the safety, health and wellbeing of people with care and support needs, but they each approach this issue in different ways.

We have heard that differing regulation of care and support services (for example, home and community care programs funded by state and territory governments, Disability Employment Services, the National Disability Advocacy Program or aged care funded by the Australian Government) gives rise to confusion for people with disability, families and carers. Differing regulation makes it difficult to consistently understand what standards of quality and safety to expect, how services and supports compare, what rights consumers have, and how to make a complaint or access support when issues arise.[2479] It also places a high burden on people with disability, families and carers to build strong knowledge and advocacy skills to navigate these systems, likely making them inaccessible given both the majority of adult participants have a cognitive disability that may mean they would benefit from support for decision-making, and the continued overrepresentation of people with disability among those experiencing digital exclusion.[2480]

Differing regulation also presents challenges for the many providers and workers who do – or are able to – provide their services under different care and support programs. This includes providers delivering supports in both the NDIS and broader disability support ecosystem (such as Disability Employment Services), as well as the wider care and support sector (such as aged care and veterans' care). [2481] As we identified through our paper 'Building a more responsive and supportive workforce' published in May 2023, few workers in the care and support sector work in traditional full-time ongoing employment and many work multiple jobs.[2482] Consistent regulation supports these much-needed workers to stay in the sector and build their skills progressively, without requiring them to stay in the same role or only work with particular subsets of clients. For example, allied health professionals have raised that the additional regulatory and administrative requirements of the NDIS may act as a disincentive to providing services.[2483]

Providers and workers have told us it can be difficult and time-consuming to understand and reconcile the information and regulatory requirements associated with different service systems, leading to duplicated effort and excessive regulatory burden. These challenges apply even in relation to different disability support arrangements administered by the Australian Government.[2484] With finite time and resources, providers have told us they need to divert resources towards process-heavy compliance activities and away from service delivery and quality improvement.[2485]

> *"The cost of doing business with the NDIS in a registered, regulated and compliant way is growing, in a highly competitive market... [the] only profitable option for services to cover overhead costs associated with regulation and compliance is to scale. This incentivises a reduction in the variety of services and provider types on offer, and*

promote one-size-fits-all, centralised service provision." – Fighting Chance Australia[2486]

"[We have] identified that the current system imposes onerous, repetitive and often inconsistent demands on providers due to the duplication of reporting requirements between state and federal authorities... if duplication and differentiation is removed... providers can meet their obligations without confusion, repetition and ambiguity." – The CEO Collaboration[2487]

"A lack of integration in Incident reporting between the [Aged Care Quality and Safety Commission] and the NDIS commission alone, creates unnecessary complexity in delivering services and care to participants. [Our] managers have indicated that an aggressive incident between two or three residents... can take between 4 – 6 hours with the full dual reporting requirements." – Provider[2488]

Our observations align with findings of consultation and surveys undertaken by the former Care and Support Harmonisation Taskforce. This consultation identified that challenges resulting from how the care and support sector is currently regulated had been observed or experienced by 75 per cent of people with care and support needs, their carers and advocates, 91 per cent of workers and 97 per cent of cross-sector providers.[2489] These challenges included:

- For people with care and support needs, carers and advocates – understanding what standards of quality and safety to expect, what their rights are and how to make a complaint about quality and safety.

- For workers and cross-sector providers – the volume of administration required to meet different regulations, navigating inconsistencies across similar regulations and knowing the different rules that apply under each program.[2490]

6.1.4. A collaborative and coordinated approach across all disability supports and all jurisdictions is required to effectively safeguard people with disability

As described in Sections 2.1.1 and 6.1.1, the activities of government agencies with quality and safeguarding roles have tended to focus on what that particular agency can do, rather than considering how the system as a whole supports the safeguarding of people with disability and the regulation of the supports they receive. Many of our recommendations and actions – including Recommendation 16 in relation to participant safeguarding and Recommendation 18 in relation to restrictive practices – hinge on all parts of the quality and safeguarding system working together under a collaborative, coordinated approach.

A collaborative and coordinated approach across the whole disability support ecosystem and all jurisdictions must be underpinned by a policy architecture that makes collaboration and coordination an imperative, and holds agencies to account for delivering on this. This should be delivered through a new Disability Supports Quality and Safeguarding Framework that covers all disability supports. This is particularly important in the context of our recommendation for a major investment in foundational supports (see Recommendation 1). It must also be supported by

capabilities and cultures within government agencies that place the holistic needs of people with disability at the forefront.

In addition to greater collaboration and coordination, national consistency in quality and safeguarding expectations for the whole disability support ecosystem and wider care and support sector would ensure people are consistently safeguarded, drive efficiencies for government, and support the market by reducing duplication and red tape.

In our federated system of government, a combination of approaches should be taken to improve the consistency of the regulation of supports and services:

- **Firstly, the NDIS Commission's coverage should be expanded to be the new National Disability Supports Quality and Safeguards Commission**, with responsibility for consistent regulation of all disability supports funded and commissioned by the Australian Government.

  This should include all disability supports provided through the NDIS regardless of how they are purchased or commissioned (including directly commissioned NDIS supports such as navigators – see Recommendation 4); as well as all other Australian Government funded and commissioned disability supports (that is, Disability Employment Services, the National Disability Advocacy Program, and all other Australian Government funded and commissioned disability and foundational supports – see Recommendation 1).

  Expanding the NDIS Commission's coverage will provide consistent protections for people with disability accessing a range of supports, reduce regulatory burden for providers, and drive efficiencies for government. The new National Disability Supports Quality and Safeguards Commission should be appropriately resourced with certainty of funding to successfully deliver on this expanded role (see Section 6.2 and Action 19.3).

  Similarities in current regulatory approaches between the NDIS and other disability supports currently provided under the *Disability Services Act 1986* will support such a transition, noting that consideration will need to be given to whether any changes are required to the *Disability Services and Inclusion Bill 2023* currently before Parliament.

- **Secondly, there should be greater national consistency in the regulation of state and territory-funded and commissioned disability supports** (for example, foundational supports such as home and community care programs, provided by state and territory governments and regulated by state and territory regulators such as the Victorian Disability Services Commissioner).

  To this end, existing efforts under Outcome 2 of the Safety Targeted Action Plan to develop nationally consistent principles for quality and safeguarding legislation and policy should continue. States and territories should also deliver targeted safeguarding support to people with care and support needs at significant risk of harm independent of whether and how they receive formal disability supports, including through Community Visitor Schemes and adult safeguarding agencies (see Actions 16.4 and 16.5).[2491]

Noting that some foundational supports will be jointly funded by the Australian Government and state and territory governments, consideration will need to be given to the appropriate regulatory

approach in these circumstances. This should ensure effective oversight without imposing unnecessary burdens on providers. Where possible, full regulatory oversight by the new National Disability Supports Quality and Safeguards Commission should be the preferred approach.

Beyond disability supports and services, the broader care and support sector fulfils a vital role in modern Australia – with over 1.8 million Australians accessing care and support through the aged care and NDIS systems alone.[2492] They deserve strong and consistent protections. There is merit in governments taking a harmonised, coordinated approach to regulation of the whole care and support sector to ensure essential safeguards are maintained while reducing regulatory burden for providers who can offer their services across programs. To this end, it is important that the Australian Government continues to build on the direction set through its draft 'National Strategy for the Care and Support Economy' towards a common approach to regulating care and support services.[2493]

6.1.5.   Action & Implementation Details

Action 19.1: The Disability Reform Ministerial Council should agree a Disability Supports Quality and Safeguarding Framework

The new Framework should replace the 2016 NDIS Quality and Safeguarding Framework. It should set responsibilities, drive coordination and underpin accountability across quality and safeguarding arrangements for disability supports within and outside the NDIS. The Department of Social Services should lead the development of the new Framework in partnership with the new National Disability Supports Quality and Safeguards Commission, the National Disability Insurance Agency and state and territory agencies, with strong engagement with people with disability.

Implementation detail:

- The Department of Social Services should lead the development of the Framework in partnership with the new National Disability Supports Quality and Safeguards Commission, the NDIA and state and territory agencies, and with strong engagement from people with disability. The Framework should have the following features:

  - Drive quality and safeguarding arrangements for all disability supports, not just NDIS supports.

  - Set clear responsibilities, accountabilities and coordination mechanisms for all government and non-government actors, including ensuring functions are allocated to the most appropriate level of government (depending on the degree to which centralisation or decentralisation of each function supports effective outcomes – see in particular state and territory functions described in Actions 16.4 and 16.5, Recommendation 18 and Action 19.2).

- Establish an approach that takes a broader lens to guide effective safeguarding interfaces between the NDIS and other service systems, articulates a balanced plan for improving both quality and safeguarding with both proactive and reactive strategies, and takes account of changes in the NDIS since the 2016 Framework was developed.

- Set out clear measures for ensuring that the disability support ecosystem is safe (including culturally), trauma-informed, and delivering quality support to people facing increased risk of systemic discrimination and inequality (for example, First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities).

- Be accessible for all audiences, including being written in Plain English.

- Sit within the architecture of the new Disability Intergovernmental Agreement (see Action 20.1).

- Be supported by ongoing monitoring and reporting on performance to hold government agencies accountable for implementation.

📄 **Action 19.2: All Australian governments should prioritise greater collaboration, consistency and timely exchange of data and information to ensure effective quality and safeguarding, including expanding the coverage of the NDIS Quality and Safeguards Commission to become the National Disability Supports Quality and Safeguards Commission**

The new National Disability Supports Quality and Safeguards Commission should have responsibility for the regulation of all Australian Government funded disability supports. State and territory governments should work towards greater national consistency in their regulation of other disability supports. Barriers to effective sharing of relevant information should also be resolved as a priority to ensure the right parties have the right information at the right time to prevent or respond to issues. Consideration of the timing for the expansion of the coverage of the NDIS Quality and Safeguards Commission should have regard to the sequencing of our reforms and those that respond to the Disability Royal Commission.

Implementation detail:

- The Australian Government should expand the coverage of the NDIS Commission to be the new National Disability Supports Quality and Safeguards Commission. It should have responsibility for the regulation of all Australian Government funded disability supports (that is, NDIS supports, Disability Employment Services and the National Disability Advocacy Program, as well as any other Australian Government funded and commissioned disability and foundational supports), noting that it may need to adopt different regulatory approaches where appropriate to the funding or delivery context.

Where possible, full regulatory oversight by the new National Disability Supports Quality and Safeguards Commission should be the preferred approach.

- As part of this, the Australian Government should transition all NDIS-related supports, including those delivered through contractual and direct commissioning arrangements, to a common regulatory approach under the new National Disability Supports Quality and Safeguards Commission. This should include transitioning quasi-regulatory requirements currently established through contractual arrangements, pricing arrangements and operating guidelines into the regulatory framework administered by the new National Disability Supports Quality and Safeguards Commission.

- The Australian Government should also consider whether any changes to the *Disability Services and Inclusion Bill 2023* currently before Parliament are required to deliver expanded coverage of the new National Disability Supports Quality and Safeguards Commission.

- State and territory governments (supported by the Department of Social Services (DSS) and the new National Disability Supports Quality and Safeguards Commission) should work towards greater national consistency in their regulation of disability supports (for example, foundational supports funded and commissioned by state and territory governments). This should include building on work under the Safety Targeted Action Plan to develop and implement nationally consistent principles for quality and safeguarding legislation and policy, and working towards greater harmonisation with the regulatory approach of the new National Disability Supports Quality and Safeguards Commission.

- DSS, the new National Disability Supports Quality and Safeguards Commission and state and territory governments, as part of implementing foundational supports, should give consideration to the appropriate regulatory approach in circumstances where foundational supports are jointly funded by the Australian Government and state and territory governments.

- DSS and the new National Disability Supports Quality and Safeguards Commission should urgently finalise the Prescribed Bodies Rule, which prescribes persons or bodies that the National Disability Supports Quality and Safeguards Commission may share information with. In doing so:

  - It is critical that this enables better sharing of information about participant risk factors (see Action 16.2); supports effective delivery of regulatory processes administered by third-party auditors (see Action 12.2) and state and territory governments (such as worker screening and the authorisation of restrictive practices – see Actions 17.4, 17.5, 18.1 and 18.2); reduces duplicative requirements for providers to report information to both the new National Disability Supports Quality and Safeguards Commission and state or territory agencies (for example, on restrictive

practices – see Action 18.1); and supports the effectiveness of Community Visitor Schemes and adult safeguarding agencies (see Actions 16.4 and 16.5) as well as the wider ecosystem of regulators.

- Strong efforts across all agencies should be made to develop the necessary culture, capability, systems and processes to support better two-way information sharing, across all parties with quality and safeguarding roles in the system, recognising the different types of information relevant to the roles and responsibilities of different parties.

• The Australian Government should, over time, move towards a common approach for the regulation of the wider care and support sector (for example, disability support, aged care, veterans' care and child care). This should start with harmonising and mutually recognising regulatory requirements across these markets, and in the longer-term considering establishing a single regulator that integrates the regulation of Australian Government funded care and support services.

6.2. The NDIS Commission was not set up for success

A large, complex system needs trusted and credible leadership with sufficient resources that can drive a well-coordinated approach to promoting and upholding the rights of people with disability. In performing this role, the new National Disability Supports Quality and Safeguards Commission must be a respected partner of the disability community that takes proactive action in their interests. While it has delivered a range of achievements to date, it is clear the NDIS Commission was not set up for success. There are opportunities to improve its capability and effectiveness, noting its central role in the future as the regulator of all Australian Government funded disability supports.

6.2.1. The NDIS Commission has not been resourced sufficiently for its scope, and does not have fit-for-purpose ICT systems

The NDIS Commission is a new regulator, still developing in its maturity and capability, with the transition period to national regulatory arrangements only recently concluded in July 2023. There has been progress in a range of areas including the development of the NDIS Code of Conduct, the implementation of a registration scheme for providers (with over 16,000 providers registered as at 30 June 2023), and nationally consistent worker screening (with over 762,000 workers granted an NDIS Worker Screening Check as at 30 June 2023).[2494] It has also exercised its Own Motion Inquiry powers to investigate issues in supported accommodation, platform providers, and support coordination and plan management.[2495]

However, the scale of the NDIS Commission's task is far larger than was envisaged when it was established. There are more participants and providers (including unregistered providers) than was originally anticipated.

This difference between vision and reality has likely contributed to consistent under-resourcing of the NDIS Commission relative to its roles and responsibilities. This was identified by the Joint Standing Committee on the NDIS inquiry into the NDIS Commission, which expressed a view that the evidence and submissions presented to it suggested inadequate staffing was a key contributor to issues raised through the inquiry.[2496]

> *"… Frontline operation teams do not have adequate employee numbers to manage the volume of reportable incidents, complaints, or compliance activities currently within the Commission's oversight. Participants are at risk due to the inability of the Commission Branch functions to perform thorough assessments to ensure the ongoing safeguarding of participants has occurred and NDIS providers are meeting legislative obligations." – Community and Public Sector Union's submission to the Joint Standing Committee on the NDIS inquiry into the NDIS Commission[2497]*

> *"Under-resourcing leads to a focus on process instead of rights and relationships. People with intellectual disabilities cannot rely on the NDIS Commission's safeguards if staff are not able to answer every call… if there isn't time to go out to meet the person face-to-face, or if investigations are put off for lack of investigators. This under-resourcing is most evident where there is a lack of specialist expertise and appreciation of the time needed to work with people who have complex communication or behaviour support needs as they work through the complaints or investigation process." – VALID's submission to the Joint Standing Committee on the NDIS inquiry into the NDIS Commission[2498]*

Submissions to that inquiry closed in July 2020. The NDIS Commission has since received funding increases through the 2020-21 and 2023-24 Budgets.[2499] Despite this, we have observed that the NDIS Commission continues to be constrained in its capacity to adopt a more proactive regulatory posture. We also note that resourcing increases have been temporary (for example, the 2023-24 Budget provided additional funding over two years).

As such, there remains a need to consider the appropriate level of resourcing for the NDIS Commission going forward. Certainty of resourcing over the next five years will be essential to ensure the NDIS Commission can plan appropriately for the full reform pathway arising from the recommendations of this Review. The need for the NDIS Commission to be appropriately funded was also reinforced by the Disability Royal Commission.[2500]

We also note that the NDIS Commission has been constrained by inadequate information and communication technology (ICT) systems and investment. This has hindered efforts to build better data capability that supports improvements in business and regulatory intelligence, meaningful reporting and a proactive data-driven regulatory posture. It has also resulted in significant inefficiencies in its own operations and missed opportunities to reduce the regulatory burden on

providers through improving the user experience of NDIS Commission portals and processes, and more timely decision-making. Better information systems are also necessary to support the quality improvement agenda through greater sharing of data and insights, as well as measurement of provider performance (see Actions 12.2 and 12.3).

> *"Renewal of NDIS Registration through the online portal was reported to take at least 8 hours due to an arduous online portal, and word limits within this system making it difficult to adequately convey the required information." – Occupational Therapy Australia[2501]*

> *"[The NDIS] Commission should... consider increasing the data it makes available to the sector, to enable providers to self-assess their performance against benchmarks and better manage their safeguard compliance." – The CEO Collaboration[2502]*

We also see a strong need to significantly uplift the digital and data capability of the NDIS Commission to ensure it is able to collect, use and share regulatory intelligence to support much more efficient and timely efforts to safeguard participants, identify and act on provider non-compliance, and support providers to engage in continuous improvement.

With the NDIS Commission now fully established nationally and developing in maturity, it is time to ensure it has the appropriate culture, capability and tools vital to enabling it to achieve its objectives. Culture and capability, as well as resourcing constraints, have contributed to current challenges with the NDIS Commission. These factors need to be better understood and solutions identified. It is time to take stock and identify the culture, capability and resourcing that it needs to be an effective and proactive regulator of the broader market of all Australian Government funded disability supports into the future. This will need careful specification and adequate resourcing.

6.2.2. The NDIS Commission has not sufficiently embedded a best practice approach to regulation

It is our observation that the NDIS Commission has not sufficiently embedded a best practice approach to regulation, in line with the Australian Government's expectations as set out in the Regulator Performance Guide (see Box 99).

Box 99: Australian Government expectations of regulators[2503]

Through the Resource Management Guide – Regulator Performance (Regulator Performance Guide), the Australian Government sets out expectations that regulators perform in line with three key principles:

- **Continuous improvement and building trust:** Regulators adopt a whole-of-system perspective, continuously improving their performance, capability and culture to build trust and confidence in Australia's regulatory settings. The Government expects all regulators to commit to continuous improvement in their processes, governance and

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capabilities, and identify and develop organisational values and a positive culture that supports best practice.

- **Risk based and data driven:** Regulators manage risks proportionately and maintain essential safeguards while minimising regulatory burden, and leveraging data and digital technology to support those they regulate to comply and grow. The Government expects regulators to weight the efficiency and cost-effectiveness of their regulatory actions, seeking to impose the least burden on those that are regulated while maintaining essential safeguards.
- **Collaboration and engagement:** Regulators are transparent and responsive communicators, implementing regulations in a modern and collaborative way.

Continuous improvement and building trust

The NDIS Commission has not been sufficiently accessible or responsive, negatively affecting public trust and confidence in the performance of its regulatory functions. Many participants and the broader community – as well as some providers – are not aware of the NDIS Commission or its role in the system. Those that are aware have told us many times that complaints processes are not accessible, and they do not receive adequate or timely responses when they raise issues.

Critically, there is a prevailing perception that the NDIS Commission 'lacks teeth' to respond to concerns about provider conduct, despite having strong regulatory powers aligned to those of other Australian Government regulators under the *Regulatory Powers Act 2014*.[2504] The NDIS Commission has a broad range of compliance and enforcement tools available to it to prevent and address breaches of the NDIS Act – ranging from education activities, through to issuing warning letters, corrective action requests, compelling the provision of requested information, and in the most serious cases banning providers or workers, revoking provider registration and seeking civil penalties.

The perception of the NDIS Commission 'lacking teeth' – as well as the ongoing high prevalence of unauthorised restrictive practices (see Section 5.1) – raise questions regarding the compliance posture of the NDIS Commission. Most of the NDIS Commission's compliance and enforcement activities focus on education activities, which is to be expected in a relatively new regulatory system to support providers to comply with regulatory requirements and is consistent with the 'Regulatory Pyramid' concept of responsive regulation.[2505] However, the low numbers of more intense regulatory responses, coupled with concerns we have heard, appear to suggest a general lack of an assertive compliance approach by the NDIS Commission in response to serious issues of safety.

> *"We assisted Lee with making a complaint to the Commission about a series of assaults they had suffered…Over the next 15 months, we frequently contacted the Commission seeking updates on the complaint but were continually met with poor communication and a lack of progress…" – Villamanta Disability Rights Legal Service[2506]*

"Literally NONE of my (valid) complaints sent to the NDIS Commission have resulted in any fair outcome, punitive action or even a timely response...There is NO oversight, NO regulatory authority and NO follow through on ensuring compliance orders on individuals long-term." – Participant[2507]

This issue was also raised by the Disability Royal Commission, which recommended that the NDIS Commission transition towards more active monitoring and enforcement (Recommendation 10.25). It also noted that the NDIS Commission's own data indicates scope for a more assertive approach, such as greater use of enforceable undertakings.

"The evidence and information before the Royal Commission indicates wide support for the NDIS Commission to adopt a more active approach to monitoring, and a stronger approach to compliance and enforcement." – Disability Royal Commission Final Report[2508]

We acknowledge that the NDIS Commission is already taking steps in this direction. This includes fines for the ongoing use of unauthorised restrictive practices, a broader use of tools such as enforceable undertakings, and an escalation of compliance and enforcement action in response to non-compliance.[2509] However, more can and should be done.

The new National Disability Supports Quality and Safeguards Commission must embed a more assertive compliance posture. This should include more active use of the full range of its compliance levers, and better communication about the action it does take to build public confidence and provide a deterrence. A dedicated review of its rules and regulatory powers should also be undertaken to ensure they are fit for purpose going forward, particularly in the context of supporting its expanded role and an active compliance posture.

Risk-based and data-driven

Issues raised throughout this chapter in relation to the lack of proportionality in current regulatory settings (see Section 3.1.5), the impact of current regulatory settings on supporting innovation (see Section 3.3.2), information sharing (see Section 6.1.2) and data and digital capability (see Section 6.2.1) highlight issues in relation to both the capacity and approach of the NDIS Commission in embedding of the principles of risk-based and data-driven approaches in its work.

Collaboration and engagement

There has been ineffective engagement by the NDIS Commission, particularly with participants, and there are limited ways through which representative and advocacy organisations can raise issues. Both government and non-government organisations have expressed frustration around what they experience as a lack of collaborative engagement from the NDIS Commission, although the strength and effectiveness of relationships appears to be mixed.[2510]

"Other concerns were raised in relation to communication from the NDIS Commission, particularly relating to notice given regarding changes to obligations and

requirements... Providers also expressed that the relationship with the NDIS Commission to date is more 'stick than carrot'"- National Disability Services[2511]

Quality and safeguarding is central to the success of the NDIS and the wider disability support ecosystem. A system this large and complex needs strong, trusted and credible leadership that can drive a well-coordinated approach to promoting and upholding the rights of people with disability. In performing this role going forward, the new National Disability Supports Quality and Safeguards Commission must be a respected partner of the disability community that takes proactive action in their interests.

To ensure it has the right data and information to advance a proactive, risk-based approach, intelligence must flow easily into the regulator and it must be a trusted partner. This can only be delivered through effective collaboration with its partners, and strong visibility, understanding and confidence in it amongst people with disability and the sector. Moving forward, people with disability and the disability support sector must have predictable, reliable interactions with the new National Disability Supports Quality and Safeguards Commission in order to build understanding of its role and confidence in its actions. Interactions need to be fit for purpose, accessible, straightforward and reliable. More open and collaborative engagement with people with disability, their supporters and the sector will build confidence. An improved understanding of the regulator's role and approach will provide the conditions for participants and the sector to raise issues and engage effectively. It is also critical to the new National Disability Supports Quality and Safeguards Commission doing its job well, by supporting its efforts to build intelligence about both issues and good practice in the market.

It is clear the current NDIS Commission is not there yet in embedding a best-practice, mature approach as the regulator of a system as complex as the NDIS. We acknowledge that the Commission has started on a path to improve including through developing a new Strategic Plan, Regulatory Approach, Data and Digital Roadmap, and Workforce Plan, as well as commissioning work to review its regulatory capability [2512]. These efforts are to be commended, and we see scope to build on them. In particular, we see opportunities to embed more activities that support proactive market surveillance and intervention, as well as proactive engagement with groups that support people with disability and more active engagement with and monitoring of providers through outreach and site visits (see Action 12.1).

6.2.3.   Action & Implementation Details

📑 Action 19.3: The Australian Government should ensure the new National Disability Supports Quality and Safeguards Commission has the resources, powers and approach to proactively and effectively regulate the disability supports market

This should include ensuring the new National Disability Supports Quality and Safeguards Commission has the right resources, capability, powers, levers and strategy to drive improved quality and safeguards in disability supports and services, and an open and transparent approach in its engagement with the disability sector. Particular focus should be given to

strengthening data and digital capabilities to support an enhanced regulatory intelligence function, and to adopting a more assertive approach to using the full range of regulatory levers available to the new National Disability Supports Quality and Safeguards Commission. The new National Disability Supports Quality and Safeguards Commission also needs certainty of funding across the next five years so it can plan appropriately for the full reform and transition period.

Implementation detail:

- The Australian Government should ensure the new National Disability Supports Quality and Safeguards Commission has the resources and capability required to deliver its functions (including under its expanded coverage, see Action 19.2, and to implement other recommendations of this Review). This may include uplifting capability and resources (both staffing and systems) and making any necessary legislative changes.

  - To support this, the new National Disability Supports Quality and Safeguards Commission and the Department of Social Services should undertake a holistic assessment of the current NDIS Commission's legislative rules and regulatory powers, with view to making changes to ensure they are fit for purpose for delivering on its future role as the new National Disability Supports Quality and Safeguards Commission.

- The new National Disability Supports Quality and Safeguards Commission should ensure it has the data and digital capabilities necessary to deliver a best-practice, proactive approach. This should build on the current NDIS Commission's Workforce Strategy and Data and Digital Roadmap, and take into account any implications of its expanded coverage (see Action 19.2).

- The new National Disability Supports Quality and Safeguards Commission should refresh its regulatory strategy and posture to embed a best-practice, proactive, risk-based approach.

- The new National Disability Supports Quality and Safeguards Commission should adopt a more active approach to using the full range of its compliance levers, with greater use of its stronger compliance levers (including in relation to unauthorised use of restrictive practices – see Action 18.1). It should also improve visibility of compliance actions to provide a deterrence and build confidence in its activities.

  - To support this, the new National Disability Supports Quality and Safeguards Commission should invest in its capacity to collect and analyse regulatory intelligence. It should use all data and tools available to identify issues, including through greater use of provider outreach activities (see Action 12.1).

- The new National Disability Supports Quality and Safeguards Commission should update external processes (such as forms and portals for providers, and complaints processes

and information about compliance action against providers and workers for participants) to ensure they meet users' needs and are intuitive and accessible.

- As part of this, performance standards for key processes (such as timeframes for provider registration and complaints handling) should be established, monitored and reported.

- The new National Disability Supports Quality and Safeguards Commission should take action to foster strong relationships and more proactive, open, and transparent engagement and collaboration with people with disability, providers and workers. This should include:

  - Building awareness of the activities of its Consultative Committee and supporting Advisory Groups, while also establishing other opportunities for people with disability, providers and workers to engage in its activities and share their perspectives and insights.

  - Embedding strong and effective engagement and collaboration with a range of stakeholders when implementing the recommendations of this Review, including in the development of the refreshed Participant Information Pack (see Action 16.3) and the Provider Risk Framework (see Action 17.81).

  - Improving external communications activities and the website experience, including to ensure information is accessible and shared regularly.

  - Implementing dedicated activities to build relationships and engagement with people facing increased risk of systemic discrimination and inequality (for example, First Nations people with disability, women, LGBTIQA+SB and culturally and linguistically diverse communities).

Chapter 6: Governance and outcomes

1. Key messages

- All people with disability should have access to supports and services that support them to fully participate in economic and social life.
- Australian governments – federal, state and territory, and local – are signatories to the United Nations Convention on the Rights of Persons with Disability (UNCRPD). This means they have obligations to provide services and supports that support accessibility and inclusion for people with disability.
- Governments have come to rely on the NDIS as the dominant source of supports for people with disability. In our chapter on foundational supports and mainstream services we have described how the gap between foundational and mainstream supports and the NDIS has grown, and those people with disability who do not have a funded package are missing out.
- This has happened for many reasons. One is that governance arrangements have helped entrench the focus on the NDIS rather than the broader service and support system. These arrangements include the way financial contributions made by governments have focused on the NDIS. Agreements and arrangements in place to deliver disability supports outside the NDIS have been unclear. As pressure on the NDIS has increased, efforts have narrowed on short term actions to respond to this pressure and contain the financial cost of the scheme.
- For people with disability, this has meant not receiving the right service at the right time, and in many cases not receiving any support. This situation can contribute to mistrust between people with disability and the broader disability support system including the NDIS. It is why we need a unified disability support ecosystem.
- We have identified five key areas where governments can take action together to establish the governance structures needed to put the unified disability support ecosystem in place.

A new compact between Australian governments

- Australia's Disability Strategy (ADS) is a strong commitment by all governments to access and inclusion. Yet its governance is disconnected from that of the NDIS and it has little funding attached. The current National Disability Agreement (NDA) which tied together funding and services and supports for people with disability is, 'outdated and (has) lost relevance'.
- A new Disability Intergovernmental Agreement is needed between Australian governments. This should bring together all disability funding and government commitments across the NDIS, foundational supports and mainstream services. We believe independent accountability measures through a Disability Outcomes Council, with similar standing to Closing the Gap is needed. This should be put in place to give people with disability confidence in governments' performance. People with disability must be present as key advisors, assessors, and designers across the unified disability support ecosystem.

A new funding approach

- Since the NDIS started in 2013, funding arrangements between governments have prioritised the NDIS. This made sense because the NDIS was such a significant reform. Yet it meant that

the maintaining and expanding of accessible mainstream and foundational supports and services were overlooked. The NDIS became, 'the oasis in the desert.'

- Funding approaches between governments will need to be different for a unified disability support ecosystem. They need to be rebalanced between the Australian Government and states and territories to share risk and create incentives for investment in non-NDIS supports and services for people with disability, including mainstream services like health and education. New funding arrangements should be linked to outcomes for people with disability.

Clarification for sustainability and governance of a new disability ecosystem

- The operationalisation of responsibility for the financial sustainability of the NDIS needs to be clarified. Roles and responsibilities of governments and agencies are unclear. This flows on to how the NDIS is operated in areas like market stewardship, and workforce planning. It also has impacts on how decisions are made by the NDIA when people with disability approach them for access and plans.
- In a unified disability support ecosystem, all governments will be responsible for the financial sustainability of the ecosystem. National Cabinet will hold ultimate responsibility. The NDIA Board should retain accountability for the sustainability of the NDIS within the legislative framework and policies affecting the broader ecosystem set by governments. Clarification of roles of governments, departments, ministers, and agencies, and the inclusion of key decisions in the NDIS Act and Rules, instead of guidelines and policy documents will make things more transparent for people with disability and support sustainability.

Development of a highly skilled, person centred, disability aware culture across all disability agencies and governments

- People with disability, their families and carers, have told us of distressing interactions with the NDIA. We have also heard that the NDIS Quality and Safeguards Commission (NDIS Commission) can do better. A disability aware and person-centred culture across governments and government agencies within a unified disability support ecosystem is critical to understanding issues people with disability face including exclusion and discrimination.
- We believe the right culture, values and training are essential ingredients for all high performing organisations. Public servants who work in disability or with people with disability – in policy, operational, or regulatory agencies - should be supported to have the right skills for the complex reforms ahead. People with disability and lived experience of disability have a key part to play in supporting this to happen. We also think this will the experiences of people with disability interacting with all supports and services across the unified disability ecosystem.

A need for better measurement, development of an evidence base of what works, and putting in place a learning system

- We want people with disability and the broader community to have more information about the benefits of the NDIS, not just the costs. The NDIS has been transformational for many

people with disability and this must be captured so the system can learn from what works, and what doesn't.

- A unified disability support ecosystem needs to be a learning system, supported by a strong research and data culture. It will be important to significantly increase funding for disability research and improve data collection across the wide diversity of people with disability and incorporate it into policy and practice. Better evidence and more effective knowledge translation will be an important foundation for a unified ecosystem. Investing more in research and data to inform better practice, innovation, sustainability, and ultimately choice and control for people with disability is essential.

2. Create a new compact between Australian Governments

2.1. A new intergovernmental agreement is needed to underpin the delivery of a comprehensive and unified disability support ecosystem

- The separation of governance, strategy and investments in NDIS bilateral agreements and broader disability commitments under the Australian Disability Strategy (ADS) creates an imbalance in the disability support system. There are few disability supports outside the NDIS and many mainstream and community services remain unavailable, inaccessible and not inclusive (see Recommendations 1 and 2).
- The disability system is reliant on Australian Government and state and territory government funding for the delivery of supports and services. The shared funding and governance of the system – how the system is overseen, structured, operated, and funded – are important drivers of its performance.
- Given these shared responsibilities, the reforms proposed in this review should be implemented in a coordinated way across the disability support ecosystem to meet the needs of all Australians with disability.
- Action is needed by all Australian governments to address the service gaps and disjointed interfaces that people with disability encounter as part of their everyday lives. Governments remain accountable for the inclusion of people with disability and the accessibility of the services that they use.
- Establishing this unified disability support ecosystem will take time. However, immediate priority should be given to developing the architecture to support a more coordinated approach. A new Disability Intergovernmental Agreement (Disability IGA) would provide a framework to govern a comprehensive and unified disability support ecosystem (see Action 20.1)
- This new Disability IGA should outline shared responsibilities between governments for an inclusive and accessible Australia as envisioned in the commitments made in the UNCRPD. The Disability IGA should also:

- Build on existing commitments made through the ADS and bring together the various strategies, frameworks, evaluation, and monitoring approaches that exist between governments to improve the lives of people with disability.

- Outline new funding arrangements (see Action 20.2) to clarify roles and responsibilities, rebalance risk sharing, develop measures to prioritise and uphold commitments to First Nations people with disability (see Action 20.4), and performance reporting against the Disability Support Outcomes Framework (DSOF) (see Action 23.1) to provide stronger assurance and accountability.

- Create links to health, housing, education, early childhood, justice, child protection and all the other mainstream service systems that people with disability need to access (see Action 20.2)

  o Link to other agreed frameworks and revised schedules, including to replace the Applied Principles and Tables of Support (APTOS) (see Action 2.6) and a new Disability Supports Quality and Safeguarding Framework (see Action 19.1)

  o Establish a Disability Outcomes Council (DOC) as an independent accountability mechanism reporting through Disability Reform Ministers to National Cabinet (see Action 20.5) to hold governments to account for commitments made through the new Disability IGA. This will help ensure the delivery of access and inclusion outcomes for people with disability.

  o Establish a new Disability Advisory Council (see Action 20.3) comprising a diversity of people with lived experience of disability to support accountability and to advice on the unified disability support ecosystem.

Recommendation 20: Create a new compact between Australian governments

⟐ Legislative change required

- Action 20.1: <u>National Cabinet</u> should agree a new Disability Intergovernmental Agreement to underpin delivery of a comprehensive and unified disability support ecosystem.
- Action 20.2: National Cabinet should agree new funding arrangements to align incentives and share costs in the disability support ecosystem.
- ⟐ Action 20.3: <u>National Cabinet</u> should establish a new permanent Disability Advisory Council reflective of the diversity of people with lived experience of disability to advise Disability Reform Ministers.
- Action 20.4: National Cabinet should develop a dedicated First Nations Schedule under the new Disability Intergovernmental Agreement to embed a First Nations Disability Forum and an independent sector-specific accountability mechanism.
- ⟐ Action 20.5: National Cabinet should establish a Disability Outcomes Council to monitor and publicly report on the performance of all governments in meeting the outcomes, commitments and benchmarks outlined in the Disability Intergovernmental Agreement.

  o

2.2.   Disability intergovernmental agreements over time

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) gives a comprehensive account of current and historic national disability policy, strategy, and governance arrangements.[2513]

Despite the best efforts of all governments, these various arrangements have at best delivered mixed outcomes for people with disability. Among the reasons for this have been imbalances in investment and risk for governments, and inconsistent measurement of and accountability for outcomes.

The current era of multilateral agreements between governments for the delivery of disability services commenced with the Commonwealth State Disability Agreement in 1991.[2514] At that time, the Australian Government took full responsibility for aged care, while states and territories agreed to take primary responsibility for disability, with limited financial support from the Australian Government. In 2007 the Senate Standing Committee on Community Affairs undertook a review of the (renamed) Commonwealth State/Territory Disability Agreement. At the time, the review recommended the next agreement between governments should include:

- A whole of government, whole of life approach to services for people with disabilities.
- A partnership between governments, service providers and the disability community to set policy priorities and improve outcomes for people with disability.
- A clear allocation of funding and administration responsibilities based on the most effective arrangements for the delivery of specialist disability services.
- A clear articulation of the services and support that people with disability will be able to access.
- A commitment to regular independent monitoring of the performance of governments and service providers.
- A transparent and clear mechanism to enable people with disability and their carers to identify and understand which level of government is responsible for the provision and funding of services.[2515]

Differing priorities between jurisdictions led to provision of very different levels of support which the Productivity Commission described as a 'postcode lottery'.[2516]

In 2008, Australia became one of the first countries to sign the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In 2009, Australia also signed the Optional Protocol, which establishes an individual complaints mechanism. Since then, structural reform within Australia's disability system has been focused towards facilitating opportunities for people with disability to fully exercise their human rights.

Also in 2008, Australian Governments agreed to adopt a new framework for federal funding arrangements through six National Federation Funding Agreements (FFAs) across disability, education, health, housing, Indigenous reform, and skills and workforce development. The National Disability Agreement (NDA) provided an overarching agreement between all Australian governments for activity undertaken to improve the lives of people with disability.[2517] It set out how

the Australian Government and state and territory governments would share the funding of services to people with disability. At the time, these services were almost all block funded and tightly rationed.

In 2010, governments agreed the National Disability Strategy 2010-2020 (NDS). This was the first time in Australia's history that all governments had committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes.[2518] The NDS was informed by the National People with Disabilities and Carer Council's Report Shut Out – the Experience of People with Disabilities in Australia, which highlighted the exclusion and discrimination people with disability reported experiencing in their daily lives.[2519]

The purpose of the NDS was to:

- Establish a high-level policy framework to give coherence to, and guide government activity across mainstream and disability-specific areas of public policy
- Drive improved performance of mainstream services in delivering outcomes for people with disability
- Give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability
- Provide national leadership toward greater inclusion of people with disability.[2520]

On International Day of People with Disability in December 2009, the Australian Government asked the Productivity Commission to undertake an inquiry into disability care and support. In 2011, the Productivity Commission's final report highlighted systemic failures in funding and delivery of services and supports impacting the ability of people with disability to participate fully in social and economic life.[2521] It concluded:

> *"The current disability support system is underfunded, unfair, fragmented, inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports... There should be a new national scheme – the National Disability Insurance Scheme (NDIS) – that provides insurance cover for all Australians in the event of significant disability. Funding of the scheme should be a core function of government (just like Medicare)." – Productivity Commission[2522]*

A well as recommending the NDIS, it also highlighted the important role of structural change in addressing this disadvantage:

> *"Broad structural change is as important as adequate funding in improving outcomes for people with a disability and their families." - Productivity Commission[2523]*

In response to the Productivity Commission's 2011 report, all Australian governments agreed to the establishment of an NDIS. It was proposed 'the development and implementation of an NDIS will be a shared responsibility of the Commonwealth and the States.'[2524]

In March 2013, the National Disability Insurance Scheme Bill 2013 was passed by the Australian Parliament. In July 2013, the *National Disability Insurance Scheme Act 2013* (NDIS Act) came into effect, the National Disability Insurance Agency was established and four trial sites were commenced in NSW (the Hunter), Victoria (Barwon), South Australia (for children and young people aged 14 and under) and Tasmania (for young people aged 15-24).

In 2013, the Australian Government established the Joint Standing Committee of the NDIS (NDIS JSC) to ensure ongoing support for the NDIS by all parties within the Parliament. The NDIS JSC is tasked with inquiring into the following:

- The implementation, performance and governance of the NDIS.
- The administration and expenditure of the NDIS.
- Such other matters in relation to the NDIS as may be referred to it by either House of the Parliament.[2525]

While this is not a formal legislative arrangement, as it is dissolved when Parliament is prorogued and then must be re-established at the start of each Parliament, the NDIS JSC has played a significant role in monitoring the progress of the NDIS and providing key insights for improvement through its inquiries, public hearings and reports.

In 2021, all Australian governments built on the NDS when they agreed to the Australian Disability Strategy 2021-2031 (ADS). This was announced on International Day of People with Disability.

2.2.1. Existing disability agreements between governments

Today, there are a range of bilateral and multilateral agreements between the Australian Government and state and territory governments on specific aspects of the disability system. However, there is no current overarching agreement which comprehensively describes the respective roles and responsibilities for the design, delivery and funding of supports and services used by all people with disability in Australia.

Australia's Disability Strategy 2021-2031

The ADS is an intergovernmental commitment to an inclusive Australian society to ensure people with disability can fulfil their potential, as equal members of the community. It is foundational to Australia's commitments under the UNCRPD. The ADS provides a framework for identifying priorities to build inclusion for people with disability.[2526] It was developed after a comprehensive consultation process in stages over three years, including around 3,000 people with disability, their families, carers, Disability Representative Organisations, peak bodies, and service providers.[2527]

Importantly, the ADS recognises the need for engagement and coordination with local government - the level of government closest to the communities in which people with disability, their families and carers live.[2528] It covers ways to improve accessibility and inclusivity in policy areas covering employment, community attitudes, early childhood, safety, and emergency management.[2529]

The ADS has a Data Improvement Plan to improve collection and sharing of data, and a commitment to consideration of how linked and de-identified data can provide deeper insights.[2530] However, while the ADS provides for these action plans and includes monitoring of progress, we have heard issues remain with governments meeting their commitments.

> *"Australia's Disability Strategy outlines the commitment and obligations of all governments to provide and make reasonable adjustments to mainstream and targeted services, supports and infrastructure systems to people with disability. In reality, most jurisdictions are failing to meet this commitment." – National Disability Services*[2531]

> *"With no Targeted Action Plan addressing human rights, it is difficult to see what, if any, actions are targeted at realising particular rights and how these will be reviewed and evaluated." – Disability Royal Commission*

We believe the ADS is an important intergovernmental commitment that should continue to drive change for the inclusion and access of people with disability. However, there are opportunities for improvement to support a unified ecosystem, including the potential for the ADS to be reshaped and significantly strengthened as part of the new Disability Intergovernmental Agreement (IGA) (see Action 20.1).

NDIS Intergovernmental and Bilateral Agreements

In December 2012, the Council of Australian Governments (COAG) signed an Intergovernmental Agreement (IGA) for the launch of the NDIS in some states (New South Wales, Victoria, South Australia, Tasmania, and the Australian Capital Territory).[2532] The IGA set out certain principles for moving towards an NDIS, including (among other things) objectives, principles, roles and responsibilities and funding arrangements. The IGA included a commitment by the Australian Government to meet 100 per cent of the risk of scheme cost overruns through higher participant numbers, higher average funded support costs and 100 per cent of the NDIA's cash flow risk. The Australian Government also agreed to meet all administrative costs of the NDIA.[2533]

Schedules to the IGA set out bilateral arrangements with all states and territories relating to the launch of the NDIS in the relevant jurisdiction, setting out the balance of cash and in-kind arrangements committed, and the planned intake of participants.[2534]

The in-kind arrangements recognised that states and territories were contributing existing programs and support types such as housing and supported independent living funding for participants, as part of their overall financial contributions. These arrangements were always intended to be temporary, given that a central tenet of the NDIS is control and choice. We have separately recommended that governments cease in-kind arrangements (see Action 2.16)

Heads of Agreement were settled with all states and territories between 2012 and 2017 which structured arrangements for the full NDIS roll-out in each state and territory. As at July 2023, all

states and territories have now fully transitioned to NDIS arrangements, although a full scheme bilateral agreement has yet to be finalised with Western Australia.[2535]

Under these bilateral arrangements, states and territories have been spending record amounts of money on disability support, but it is nearly all directed to the NDIS. Supports within the NDIS made up more than 93 per cent of all disability funding in 2021-2022.[2536] Further consideration of the impacts of these bilateral arrangements are in Chapter 1.

Applied Principles and Tables of Support (APTOS)

The Applied Principles to Determine the Responsibilities of the NDIS and Other Service Systems (APTOS) were originally agreed by the Council of Australian Governments (COAG) in April 2013 and were updated in 2015 to account for the early experiences of the NDIS trials.[2537]

The APTOS sets out guiding principles to determine roles and responsibilities of the NDIS and other service systems for funding and delivery of services, across 11 different mainstream interfaces. It is the primary document that governments use to determine which service system is best placed to provide supports people with disability.

We have heard from key stakeholders that the principles contained in APTOS has not translated into consistent collaboration on the ground and is not achieving its intended aims. The underlying structure of APTOS which primarily focuses on boundaries is part of the problem - it assumes people with disability will be supported by the NDIS or another system. In reality, many people with disability need support from multiple service systems, often concurrently.

> *"Currently, all three tiers of government do not cooperate or collaborate in order to achieve the best outcome for an individual. There is a push and pull between departments with everyone protecting their funding." – Autism Advisory and Support Service* [2538]

We recommend the APTOS be replaced with a multilateral schedule (see Action 2.6) under the new Disability IGA (see Action 20.1). The schedule should clarify the core principles for how the NDIS and other services systems will operate, provide detail on shared responsibilities and update and clarify single system responsibilities.

Federation Funding Agreements

The Intergovernmental Agreement on Federal Financial Relations (IGA FFR) sets out objectives, principles, and institutional arrangements between the Australian Government and state and territory governments for the purposes of financial relations. The IGA FFR is the key foundational document underpinning funding agreements between the Australian Government and state and territory governments. There are existing sectoral FFAs for Health, Education and Skills, Infrastructure, Environment, and Affordable Housing, Community Services and Other. Future

directions for FFAs and opportunities for practical clauses for disability support are discussed in Section 2.5.4 and in Action 20.2.

Other agreements

There are a range of lower level agreements, frameworks and strategies agreed by governments for specific elements of the disability support ecosystem – for example, the NDIS Worker Screening Check, the NDIS Quality and Safeguarding Framework, and the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector. [2539] [2540] [2541] These have been developed by governments over time since the commencement of NDIS trials in 2013.

2.2.2. The current governance arrangements were a good first step

Following years of advocacy by people with disability to realise the possibility of the NDIS, the agreements struck in the past decade have been essential in the transfer of previously existing disability programs and additional contributions from all parties into a national system.

Transition to the NDIS was always going to be a complex exercise given the variety of program and funding arrangements in each state and territory, the ambitious timeframes for transition, and the movement of some additional elements of formerly state and territory system responsibilities to a centralised authority.

The establishment of the NDIS is a major achievement for people with disability who advocated for it. All governments and all political parties are also to be congratulated for championing the NDIS and for working together to structure and deliver it from previous diverse systems. Service providers have also played a key role in supporting participants, while needing to transition their businesses from block to individualised funding.

While there was an IGA established at the launch of the NDIS, this ceased after the first three-year launch or trial period of the scheme. Since that time, the governance framework has been bilateral, between the Australian Government and each state and territory. This bilateral approach reflects the fact that each state and territory had different disability systems which needed to transition to a national and consistent structure and so a bilateral approach was essential for the establishment and transition to full scheme stages of the NDIS.

The ADS is a step forward towards improving collaboration between governments to address the concerns of people with disability that previous arrangements under the NDS were disjointed.[2542] The vision and goals of the ADS have strong support from the disability sector.[2543]

2.2.3. However, there are improvements that could be made to support a unified ecosystem and deliver better outcomes

Governments have an obligation through international and domestic commitments (including the UNCRPD and discrimination law) to ensure all government services are accessible and inclusive to support people with disability achieving full social and economic participation. This includes the transport, hospital, early childhood and education and justice systems.

Accessible and inclusive mainstream service systems contribute to people with disability achieving better health, education, social and economic outcomes. However, this is not always being achieved, as evidenced by the Australian Institute of Health and Welfare, which reported in 2022 (see Box 100).

Box 100: People with disability continue to experience poor social and economic outcomes

In 2018, adults with severe or profound disability are almost nine times as likely as adults without disability and almost twice as likely with adults with other disability to assess their health as fair or poor.[2544]

Of people aged 15 to 64 with disability acquired before the age of 15, more than 1 in 5 left school before age 16 compared to 1 in 11 of their peers without disability.[2545]

They also experience lower labour market participation rates than their peers (53 per cent compared to 84 per cent) and are twice as likely to experience social isolation (17 per cent compared to 9 per cent). The gap in social isolation is highest for people aged 15 to 24 where 18 per cent of people with disability experience social isolation, compared to 7 per cent of people without disability.[2546]

Some submissions to this review posit that funding and governance of the disability system does not support a complete unified disability support ecosystem:

> *"The Tasmanian Government agrees that current funding and governance arrangements do not provide for a complete and joined up system of support and that new approaches are needed to ensure Tasmanians with disability do not fall through the cracks and miss out on much needed support." - Tasmanian Government[2547]*

People with disability told us of the impact of governments not working together across the disability support system:

> *"The time for the NDIS and State Governments to work together and acknowledge the harm experienced by people with intellectual disability who fall between the gaps of services provided by different levels of government is well overdue... The disconnect between the Federal and State Governments causes harm and compromises quality and safety in the services people with intellectual disability receive." – VALID[2548]*

While the ADS has only been in operation for a short time, we have identified a number of issues that are likely to limit its effectiveness. Many of the activities in the ADS represent jurisdiction-specific programs that were in place prior to the ADS being agreed. While the ADS is a commitment of governments in the form of an IGA, there are limited funds tied to the ADS, nor is performance assessed independently of government to ensure accountability, apart from self-reporting where data exists.

Over the past ten years, governments have prioritised the establishment and funding of the NDIS. This has stretched state and territory resources.

> *"In the early days of the NDIS there was promulgated a sense that "disability" as a government issue was transferring to the Commonwealth from the eight States and Territories, who had grossly underfunded the needs of people with disabilities. This belief, that permeated Treasuries, senior State government executives and State Ministers, led to the situation where States counted every dollar they could conceivably have been spending on disability and offered it all (or nearly all) to the Commonwealth as the State's contribution to the NDIS." - Attorney-General's Department, South Australia* [2549]

At the same time, existing arrangements create incentives for a shifting of disability support responsibility to the NDIS as the Australian Government currently bears 100 per cent of marginal costs for NDIS growth and this has adverse consequences for people with disability.

> *"...Work must be undertaken towards a new disability funding settlement designed to secure matched effort and investment between NDIS and non-NDIS efforts for people with disability...A new equilibrium could be the centrepiece of a drive towards true sustainability for the NDIS, better outcomes for people with disability that meet out CPRD obligations and a legacy of better services for all Australians." - Advocacy for Inclusion* [2550]

2.3.   A new compact between Australian governments is critical to establish the disability support ecosystem success

Past reviews dating back to the Joint Standing Committee on Community Affairs (2007) and, since then including, the NDIS JSC (2015), Productivity Commission Inquiry into the NDA (2019) and the Tune Review (2019) have consistently identified elements which need to be addressed through governance arrangements to deliver the outcomes that people with disability need and governments intend:

- Supports and services must be delivered in a way that assists people with disability to move easily between specialist and mainstream systems as their needs change.
- Clarity must be provided about roles and responsibilities of governments, and associated levels of funding.
- People with disability must understand what supports and services they can expect.
- Better data is needed to demonstrate what works for people with disability and the benefits achieved through investment.

In terms of previous recommendations for strengthening governance arrangements, the Productivity Commission inquiry into the NDA is both the most comprehensive and significant. It described the NDA as being out of date and not reflecting contemporary policy settings.[2551] As a consequence, the Productivity Commission found the NDA, '...is a weak driver of disability policy and reform actions.'[2552] It recommended that:

"An overarching agreement is needed to clarify the relationship between all aspects of the disability policy landscape and to facilitate cooperation between governments and promote greater accountability. Further, the Commission is of the view that a national agreement is likely to be the most effective instrument to influence and drive government policies and practices to achieve the agreed outcomes." - Productivity Commission[2553]

More recently, the Department of Social Services (DSS) submitted to the Disability Royal Commission in October 2021 that, 'the NDA has limited practical application moving forward.'[2554]

The Productivity Commission also highlighted the importance of an aspirational objective for disability policy in a new agreement, the roles and responsibilities of people with disability to achieve this, what outcomes a new agreement would drive, and the need for a consistent framework to track progress against outcomes.[2555] The Productivity Commission's proposal for a new NDA is set out in Figure 166 below.

Figure 166: The Productivity Commission's 2019 proposal for a new National Disability Agreement
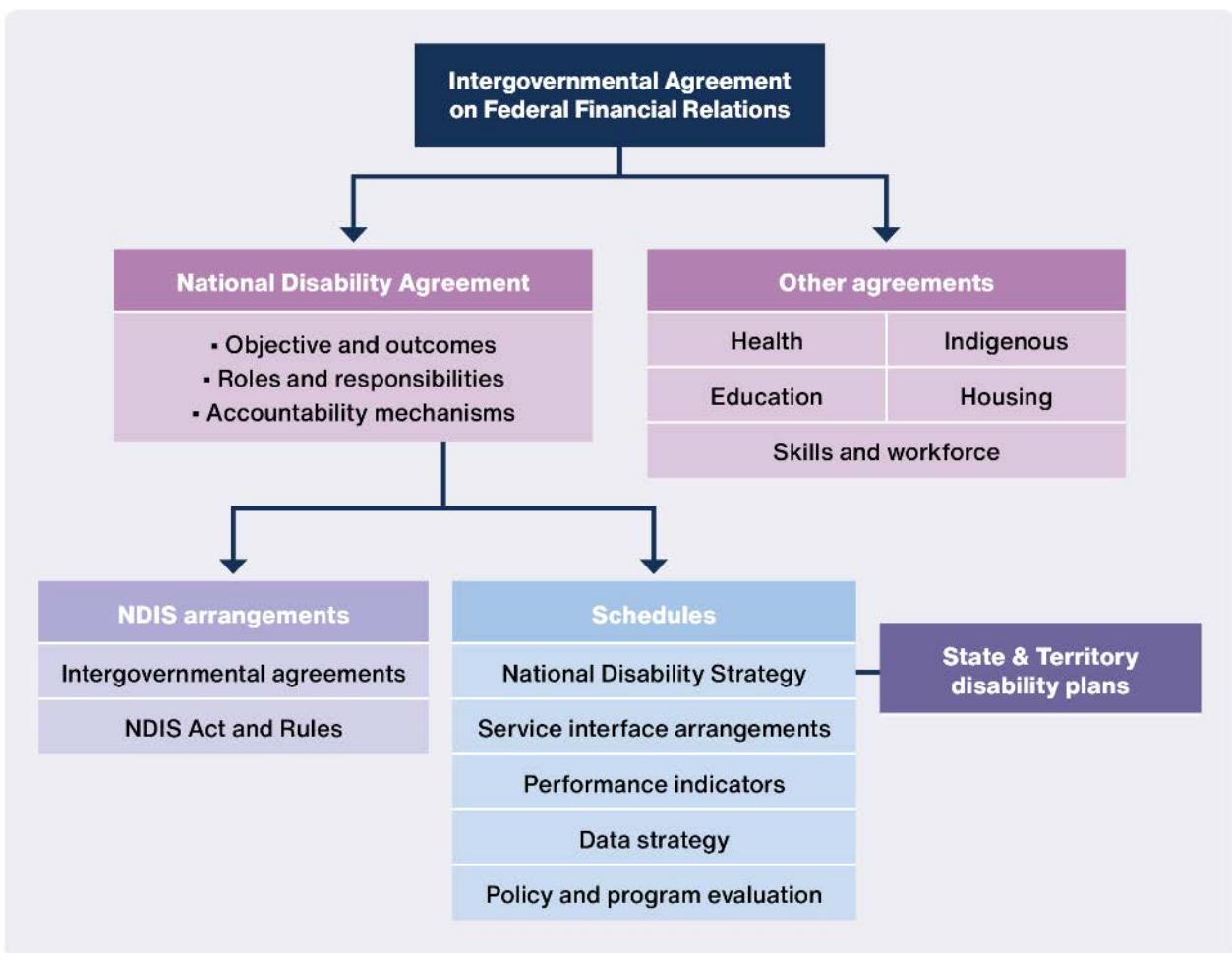
The diagram is from the Productivity Commission's 2019 report: p60.

The need for new unifying governance arrangements has been highlighted most recently and most comprehensively in the final report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission). The Disability Royal Commission's recommendation includes that the, 'fundamental objective of the (new) agreement should be to advance equality, inclusion and the rights of people with disability in Australia.'[2556]

2.3.1. A new Disability IGA to underpin delivery a comprehensive and unified disability support system

Given the need for a new overarching disability agreement between governments was first identified in 2007 and many reviews and inquiries since have also pointed to the need for an overarching agreement, there is both a long history and deep evidence for the need for governments to put in place via a new multilateral and unifying Disability IGA.

This agreement should aim to ensure equality of opportunity for all Australians with disability and to strengthen the delivery of Australia's commitments under the UNCRPD. The recommendations from the Productivity Commission review of the NDA in 2019 and the Disability Royal Commission provide an ideal starting point.

A new Disability IGA should bring together existing and proposed intergovernmental initiatives to underpin delivery of a comprehensive and unified disability support system. It should give people with disability, their families, and carers assurance that all levels of government are taking real and measurable actions to focus on an accessible and inclusive society.

> *"We believe that a complete and joined up ecosystem of support is not just about the NDIS, but is about support for all people, whenever it is needed. This responsibility should be shared among all levels of government, as well as the community, NGO's and business sectors. The supports need to consider the whole-of-family needs and context, working alongside the family and other services engaged with them."- The Salvation Army[2557]*

We heard broad support from a range of stakeholders for a new Disability IGA. They highlighted the importance of a new agreement taking a whole of life approach for people with disability. Governments working together to commit to inclusive and accessible mainstream and foundational supports also featured.

> *"Disability services that reach where the NDIS cannot and does not reach must be maintained and – in many cases – reinstated. Among other things, this requires an equilibrium of effort and investment between the NDIS and the Australian Disability Strategy. We suggest a new settlement between jurisdictions designed to shift investment towards lasting social and community infrastructure. This should be the main sustainability outcome from the NDIS Review – caps, cuts and exclusions from the scheme are an inferior and problematic way of achieving sustainability." - Advocacy for Inclusion[2558]*

The Commonwealth government should have negotiated a more detailed agreement for the role of the Commonwealth through the National Disability Insurance Agency (NDIA) and the Department of Social Services (DSS) and the role of the States/Territories. This should have been a Commonwealth States and Territories Disability Agreement with teeth…" – Attorney General's Department, South Australia[2559]

We have also heard about a need for stronger accountability settings in new disability support ecosystem arrangements:

"To create a joined-up ecosystem of support [we agree] that a whole of government approach is needed…The NDIS Review has suggested that an intergovernmental agreement could be developed to support better system integration. History suggests that an agreement of some sort that will hold governments publicly and fiscally accountable will be required to ensure that these services are available to support people with disability." - National Disability Services[2560]

"a stronger rights-based intergovernmental agreement for disability inclusion, and whole-of-government commitment, investment, performance measures, shared goals and mechanisms to address entrenched marginalisation of people with disability and to drive inclusion of people with disability in services and activities available to all other Australians." - Brotherhood of St Laurence[2561]

The establishment of a unified disability support ecosystem incorporating integrated and inclusive supports for people with disability through mainstream and foundational supports will have the practical effect of guaranteeing support for people with disability.

A new agreement and restructure of this magnitude will require governments to work together in new and cooperative ways. This means renewed practical commitments to the UNCRPD as well as new and innovative approaches to formal relationships, funding, and accountabilities between governments. It will require deeper engagement from Disability Reform Ministers and strengthened government departmental capabilities at Australian Government and state and territory levels.

Our recommendation for a new Disability IGA aligns with recommendation 5.1 of the Disability Royal Commission's report.[2562]

2.3.2. Elements of a future Disability IGA need to incorporate all aspects of the disability support system

A new comprehensive and unified disability support ecosystem should include the elements set out in Recommendation 1 and 2. These include expansion of the foundational support sector, and accessible and inclusive mainstream supports. We propose a structure for a future Disability IGA that draws together the fragmented elements of the current system and incorporate our proposed reforms to achieve inclusion and accessibility for people with disability (see Figure 167 below).

Figure 167: A new Disability Intergovernmental Agreement to underpin delivery of a unified disability support ecosystem
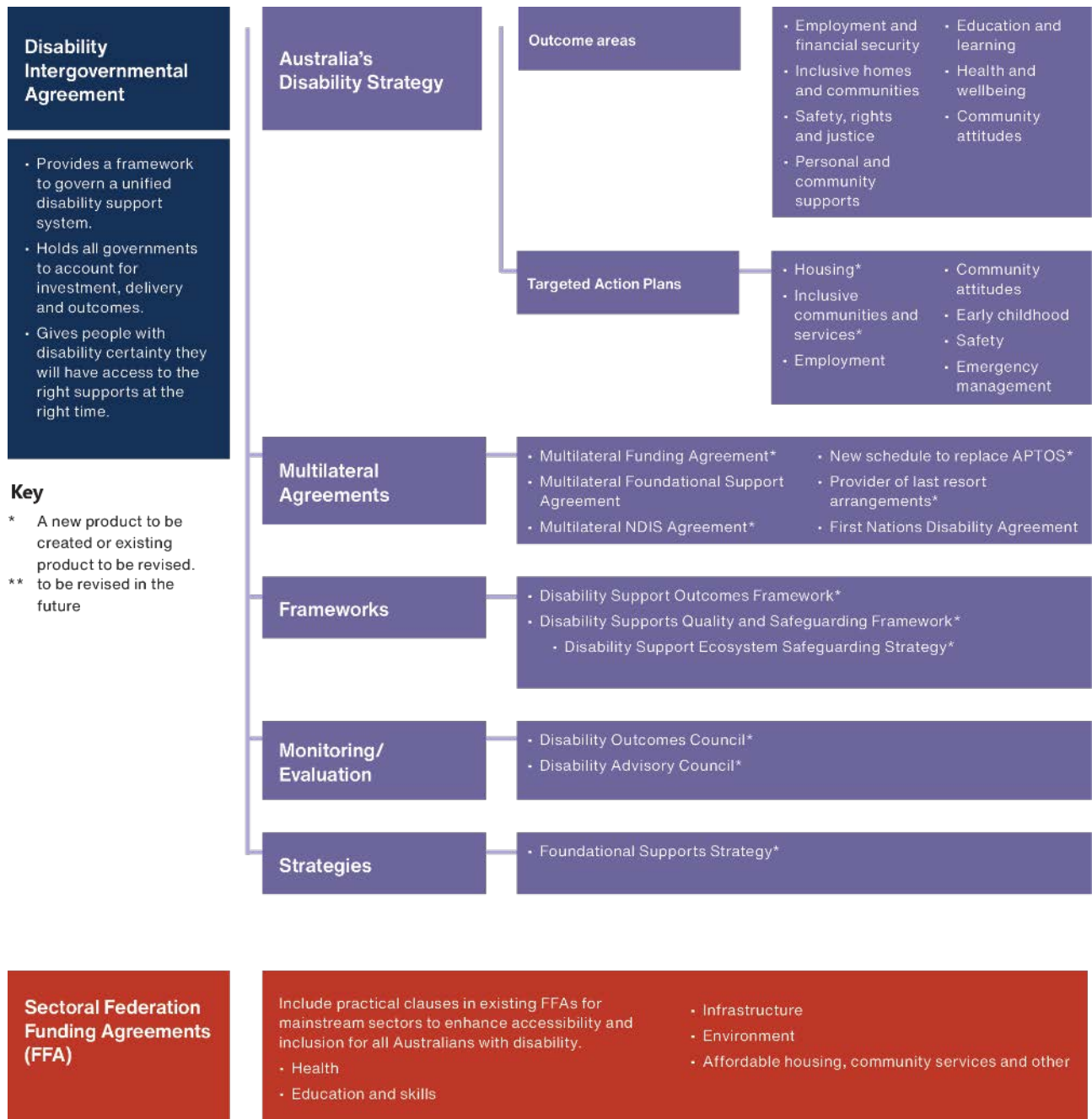
Our proposed model involves:

- The ADS as the foundational schedule, representing all Australian governments' commitments to an inclusive and accessible society, and include Targeted Action Plans for:

  - Housing Targeted Action Plan (see Action 9.11)

  - Inclusive Communities and Services Targeted Action Plan (see Action 2.1).

- New frameworks including a:

-   Disability Support Outcomes Framework (see Action 23.1)

-   Disability Supports Quality and Safeguarding Framework and Disability Support Ecosystem Safeguarding Strategy (see Actions 16.1 and 19.1)

-   New independent monitoring and evaluation bodies including a:

    -   Disability Outcomes Council (see Action 20.5)

    -   Disability Advisory Council (see Action 20.3)

    -   Disability Research and Evaluation Fund (see Action 23.3).

-   New strategies, agreements and policies to target areas of shared focus, including a:

    -   Multilateral funding agreement which should rebalance risk and investment and refresh accountabilities between the Australian Government and state and territory governments (see Action 20.2)

        o   The multilateral funding arrangements should reflect the NDIS Financial Sustainability Framework agreed by National Cabinet in April 2023, future funding arrangements for the NDIS, and future funding arrangements for the equal funding of foundation supports. Taken together this should have the practical effect of guaranteeing support for all people with disability whether through mainstream, foundational or individually funded disability supports

    -   Schedule including principles for determining responsibilities to replace the APTOS (see Action 2.6)

    -   Policy on provider of last resort arrangements, which will ensure participants have continued access to supports where markets fail (see Action 13.4)

    -   A First Nations schedule under the new Disability IGA to embed a First Nations Disability Forum and an independent sector-specific accountability mechanism (see Action 20.4)

    -   Foundational Supports Strategy (see Action 1.2), ideally designed, funded and commissioned by all governments.

Figure 168 below shows our proposed new governance structure and roles and responsibilities across government agencies for a unified disability support ecosystem.

Figure 168: A new governance structure for a unified disability support ecosystem
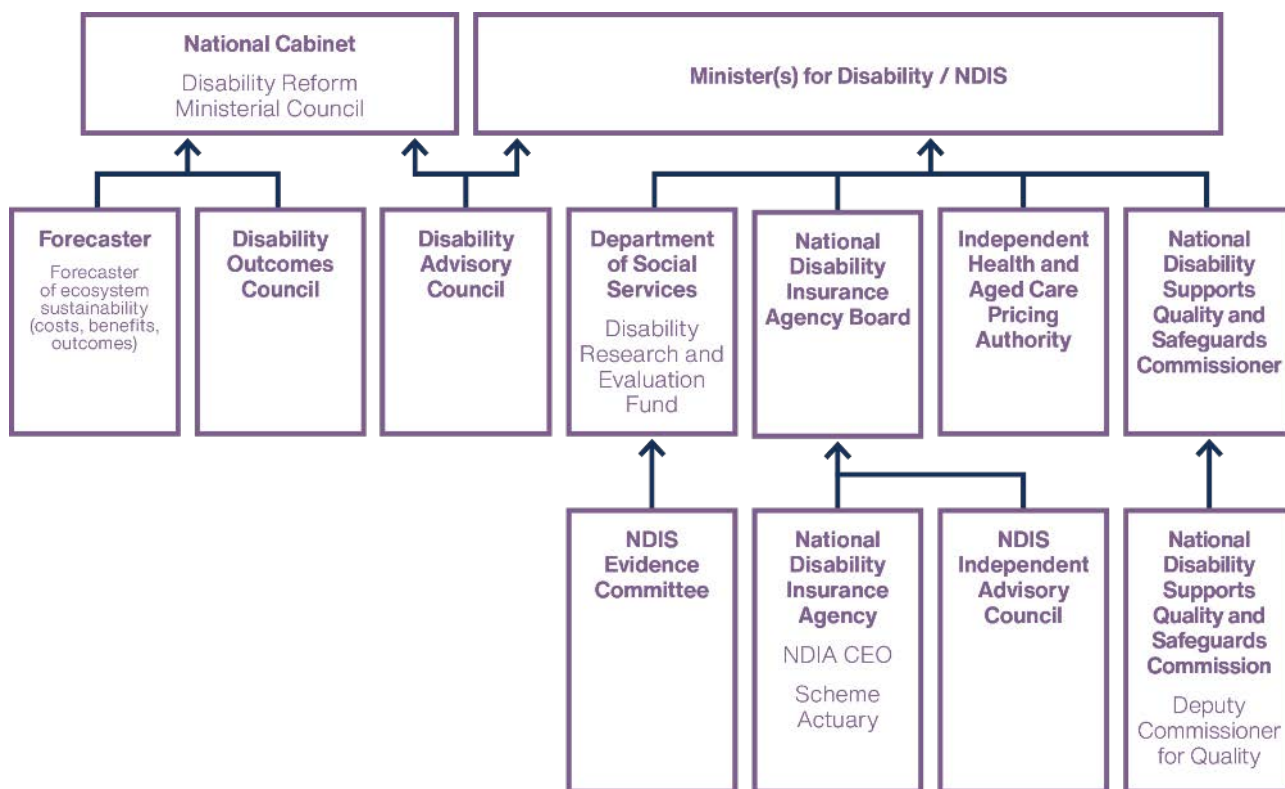
We believe National Cabinet should be ultimately accountable for establishing and driving the new Disability IGA and associated mechanisms – for example the Disability Advisory and Disability Outcomes Councils (Actions 20.3 and 20.5). This approach recognises the cross-cutting nature of the work involved and the importance of these new intergovernmental arrangements in delivering strong progress to the full inclusion of Australians with disability in work, community, and social life and reforms to mainstream services to ensure that they are universal and so serve the needs of people with disability.

2.3.3. Action and Implementation Details

Action 20.1 National Cabinet should agree a new Disability Intergovernmental Agreement to underpin delivery of a comprehensive and unified disability support ecosystem.

This Intergovernmental Agreement (IGA) should build on the foundation of Australia's Disability Strategy and confirm the commitment of all governments to the United Nations' Convention on the Rights of People with Disability. It should include measurable commitments and targets for improving the accessibility and inclusivity of mainstream services and the range and level of foundational services (see Recommendations 1 and 2), as well as ensuring Australian governments are accountable for the future success and sustainability of the NDIS (see Action 21.1). It should have the practical effect of guaranteeing support to all people with disability — not just those in receipt of NDIS-funded supports. Progress in meeting commitments should be independently assessed by a new Disability

Outcomes Council (see Action 20.5). This should complement the role for the Productivity Commission in overseeing priority IGAs, such as progress under Closing the Gap.

Implementation detail:

- The Department of Social Services (and any other relevant agencies) should lead the development of the new IGA and related schedules in collaboration with states and territories to take effect from 1 July 2025. The IGA should include schedules on the following:

  - the commitments of all governments to implement the United Nation's Convention on the Rights of Persons with Disabilities

  - the roles, responsibilities, expectations, outcome measures and targets for each level of government in providing:

    o accessible mainstream (universal) supports, including funding agreements to drive action and delivery
    o foundational disability supports, including funding agreements
    o These should have practical effect of guaranteeing support for all for all people with disability whether through accessible mainstream, foundational or individually funded disability supports. This could include a mechanism to support a complaints mechanism for people with disability about failures to deliver supports for people with disability in mainstream service settings or in foundational supports.

  - a multilateral NDIS funding agreement, replacing the core components of current bilateral agreements including funding shares for the NDIS

  - a multilateral schedule as a new accountability mechanism to clarify responsibilities and improve system integration between the NDIS and other service systems, replacing the Applied Principles and Tables of Supports (see Action 2.6)

  - a new Targeted Action Plan for Housing (see Action 9.11)

  - a revised national Disability Support Quality and Safeguarding Framework (see Action 19.1)

  - a new Disability Support Outcomes Framework (see Action 23.1)

  - a dedicated First Nations' schedule under the IGA to embed a sector specific partnership and an independent accountability mechanism. reporting requirements, data improvements and collection (see Action 20.4)

  - Establishment of a Disability Outcomes Council (see Action 20.5) to improve transparency and accountability across the disability support system. This Council will be responsible for monitoring, reviewing, and reporting on the investment, outcomes, and benefits of all governments across the new disability support system using the

new Disability Outcomes Framework (see Action 23.1) and commitments made by all governments under the Intergovernmental Agreement.

2.4. Funding arrangements between governments have focused on the NDIS at the expense of accessible mainstream and foundational supports and services

In our earlier chapters on foundational supports and mainstream, we identified the imperative for all Australian governments to ensure foundational supports are in place and mainstream services are accessible to create a unified and comprehensive disability support ecosystem. Beyond governance arrangements, we consider funding arrangements are a key factor driving inequity between people with disability in receipt of an NDIS package and those who are not. These arrangements were set up to support the roll-out of the NDIS. However, the impact on the broader disability support system has been detrimental.

2.4.1. Funding arrangements have prioritised the NDIS

In its 2011 inquiry, the Productivity Commission recommended the Australian Government fully fund the NDIS. However, from the Productivity Commission's perspective, the less-preferred financing option for a pooled funding approach was selected by governments.[2563] The shared approach had other benefits, however, including ongoing engagement of states and territories in the governance of the NDIS. Agreements were established bilaterally due to the individual nature of transition and contribution arrangements of each state and territory as their existing arrangements transitioned to the NDIS.

Initial funding arrangements between the Australian Government and states and territories for host jurisdictions were as follows:

* Shared funding for individual support packages for people with disability in the NDIS.
* Australian Government to meet any cost overruns associated with higher participant numbers, higher average NDIS funded support and 100 per cent of the NDIA's cash flow risk and any other risk sharing arrangements during launch and transition to full scheme. The Australian Government would also carry full costs for the NDIA for establishment, administrative, system support costs, workforce and sector development.[2564]

Heads of Agreement were signed progressively between the Australian Government with states and territories from 2012. They outlined timeframes and transition to full scheme arrangements. They provided for state funding to be subject to an escalation rate. This was initially set in Heads of Agreement at 3.5 per cent and then was increased slightly to 4.0 per cent from 2018-19, following the findings from the Productivity Commission 2017 Review of NDIS Costs.[2565]

Full scheme bilateral agreements (noting an agreement is yet to be settled with Western Australia) committed the states and territories to similar arrangements to each other while the Australian Government agreed to be responsible for the balance of all NDIS costs, taking into account the financial contributions from (states/territories). [2566]

2.4.2. Bilateral arrangements have driven imbalances in funding as well as the system

When the NDIS was introduced, bilateral agreements were designed in the context of the original Productivity Commission projections, which envisaged the scheme would support far fewer people than it does today.

In 2011, the Productivity Commission estimated that the NDIS would support 411,000 participants and have an annual gross cost of $13.6 billion by when the scheme was expected to be fully implemented and mature in 2018-19.[2567] In its 2017 report, the Productivity Commission expected the scheme to reach maturity by 2019-20 with 476,000 participants and an annual cost of $22 billion.[2568] It is notable these forecasts were for a point in time and could not take into account unanticipated events with costs impact. For example, initial estimates did not take account of major wage increases through adjustments to the Social, Community, Home Care and Disability Services (SCHADS) Award in 2022 and did not account for the inclusion of developmental delay and ageing in the scheme.

The DisabilityCare Australia Fund (DCAF) was established in 2014 through the *DisabilityCare Australia Fund Act 2013* (the DCAF Act). It was established to support the contributions of states, territories, and the Australian Government for expenditure made for the NDIS and is funded from a 0.5 per cent increase in the Medicare Levy.[2569]

In the first years of transition, the pace of roll out was less than expected. With fixed funding from the states and territories, the accumulated unspent funds were retained by the Australian Government and proposed to be used for a Reserve Fund. The future use of the Reserve Fund has not been resolved.

When the NDIS commenced, it was thought appropriate the Australian Government should be the 'underwriter' of the NDIS, because the Australian Government has access to greater sources of revenue than states and territories. However, the extent of the underwriting and hence significant impact on the Australian Government budget in recent years was not expected.

In more recent years, as the number of participants has exceeded the Productivity Commission estimates and average package costs have risen more than expected, the caps in the bilateral agreements on the growth in state and territory financial contributions, has meant the Australian Government has been responsible for the balance of all NDIS cost growth (that is, 100 per cent of the marginal costs over and above the fixed caps).

As at June 2023, the scheme supports just over 610,000 participants, at an annual cost of $35.1 billion in 2022-23.[2570] This has seen the Australian Government's share of funding for those aged under 65 costs rise from the originally agreed 50 per cent to 59 per cent in 2021-22, while the state and territory governments' contributions have fallen to a combined 41 per cent.[2571] Under current settings, in 2032-33 the Australian Government's share will rise further to 78 per cent, while the state and territory contribution will fall to just 22 per cent (see Figure 169).

Figure 169: State and territory contribution to the NDIS (0-64 years), 2019-20 – 2032-33
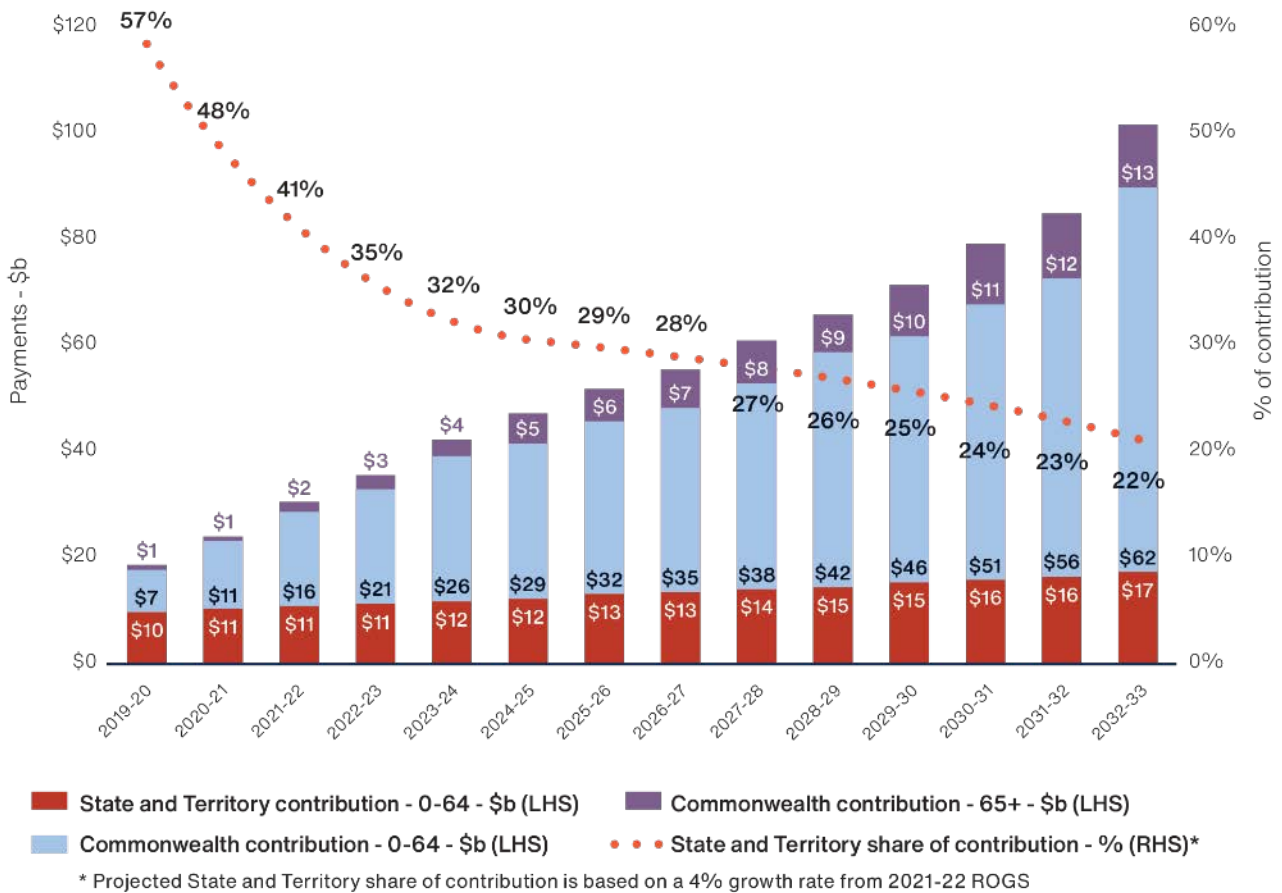
While the NDIS represents a significant and increasing investment by states, territories, and the Australian Government, the funding arrangements have created perverse incentive for states, territories and other service systems which are capped to shift costs to the NDIS and underinvest in mainstream supports. Existing settings contribute to a lack of shared vision and insufficient cooperation to improve outcomes for all people with disability. As a result, the disability ecosystem is not sufficiently healthy or unified and the NDIS has become a seemingly limitless resource.

We have heard about the practical implications of existing funding arrangements between governments for people with disability.

> *"The current system rewards government departments for keeping costs down, thereby causing these departments to seek to keep people out of their systems, or to access smaller amounts of service than is beneficial. This Review seeks feedback about outcomes-based performance for providers of NDIS services, but similar incentives for government and community services should also be in place, so that they can also steer away from a focus on financial outcomes."* - Autism Queensland[2572]

> *"the creation of the NDIS gave excellent political cover for this act of negligent cruelty with political commentary more interested in the risk of overspending on vulnerable*

people in the NDIS and not the desertion of vulnerable members of our community by the states. The solution to 40 years of underfunding was never going to be merely re-shuffling the existing funds and this approach was doomed to create such a disability desert, with one clear waterhole." – Mental Health Carers NSW[2573]

2.4.3. Funding between the Australian Government and the states and territories should be rebalanced

More investment is not enough. There is a need to rebalance incentives, responsibilities, and roles across governments to ensure financial incentives and risks for governments, as well as investments, are shared for both the NDIS and foundational supports. This should involve more proportionately aligned financial contributions, clearer roles and responsibilities, and increased accountability. By sharing funding, risk and accountability in this way, governments should be incentivised to work together to ensure funds are invested appropriately across the whole disability support ecosystem to deliver stronger outcomes for all people with disability.

The responsibilities of the states and territories within the NDIS Act have remained the same since 2013, despite their limited exposure to scheme financial risk. Co-sharing of risk and investment is critical to a unified system. Going forward, decision making powers within the NDIS Act for parties should be shared in a manner proportionate to shared investment.

The current funding arrangements for the NDIS are built on bilateral agreements which have developed to meet the staged nature of the NDIS rollout, both between states and territories and within jurisdictions, where different parts of the former disability support arrangements transitioned at different times. This jurisdiction by jurisdiction approach has resulted in a gradual move away from the multilateral arrangements that had previously been agreed through the NDA. Now the transition to the NDIS is complete, it is appropriate to move back to a multilateral arrangement to ensure a more coherent, shared approach.

Earlier this year, National Cabinet agreed to the need for a new NDIS Sustainability Framework which will establish an annual growth target of 8 per cent in the total costs of the scheme from 1 July 2026.[2574] We consider that as part of this new multilateral approach funding of NDIS growth should be shared to better align risks and incentives. Options include fixing the ongoing shares of those aged under 65 at the 2026-27 level or equally sharing the future growth in costs (potentially with an 8 per cent cap on the contributions from states and territories).

The same approach to sharing funding to align risks and incentives should apply to investment across the disability support ecosystem, including to deliver foundational supports, with a sense of shared and equal purpose. This would be best achieved through a sharing of the costs of foundational supports between the Australian Government and state and territory governments on a 50:50 basis. Contributions made by states and territories should continue to be based proportionately on population shares.

These new shared financial responsibilities should be documented in a new multilateral funding agreement which forms a schedule to the new Disability IGA.

2.4.4. Federation Funding Agreements should also be strengthened to promote accessibility and inclusion of people with disability

It is also important that governments address inclusion and accessibility through mainstream funding arrangements. The existing IGA on Federal Financial Relations provides for sectoral Federal Funding Agreements (FFAs) which underpin payments to states and territories for coordinated action. These include Health, Education and Skills, Infrastructure, Environment, and Affordable Housing, Community Services and Other. The FFAs sit alongside National Agreements including (for example) the National School Reform Agreement, the National Health Reform Agreement and the National Housing and Homelessness Agreement.

The Productivity Commission Study of the NDA in 2019 considered these arrangements. It recommended:

> *'To enshrine the cross-cutting nature of the National Disability Agreement (NDA), the obligations of governments under the NDA should be reflected in other National Agreements — and, where relevant, other Commonwealth–State agreements. To facilitate this, the new NDA should include a commitment to reflect, in those other agreements, the responsibilities, performance targets and policy commitments of governments under the NDA.' – Productivity Commission*[2575]

The Disability Royal Commission also considered national agreements, strategies and plans affecting people with disability. Commissioners proposed (recommendation 5.4) the Australian Government and states and territories undertake a review to consider:

- the alignment of national agreements, strategies and plans with ADS
- how funding allocations recognise the needs and rights of people with disability
- the inclusion of specific outcomes measures for people with disability
- the development of specific action plans relating to people with disability. [2576]

We believe the Council on Federal Financial Relations (CFFR) should continue to work to strengthen FFAs to improve outcomes for people with disability and to align with commitments made through the ADS.

The inclusion of new practical clauses to promote inclusion of people with disability and increased accessibility in mainstream services should be prioritised. These new practical clauses should detail mainstream service responsibilities and service delivery obligations towards people with disability, with inclusion of performance and outcomes measures for the clauses included in the Disability Supports Outcomes Framework (see Action 23.1). The DOC should establish a mechanism to monitor and publicly report on the investment and performance of all governments in delivering inclusive and accessible mainstream services. This will be complemented by the recommended legislative reforms in Action 2.1.

Action 20.2: National Cabinet should agree new funding arrangements to align incentives and share costs in the disability support ecosystem.

A new multilateral Federation Funding Agreement schedule to the new Disability Intergovernmental Agreement should reinforce shared accountabilities for the whole ecosystem. For foundational supports, costs should be shared equally (50:50) between the Australian government and state and territory governments. From commencement of the agreed NDIS Financial Sustainability Framework growth target in 2026-27, future increases in NDIS costs should be shared in a way that better shares risk and aligns incentives. Options include fixing the ongoing shares of those aged under 65 at the 2026-27 level) or equally sharing the future growth in costs (potentially with an 8 per cent cap on the contributions from states and territories). The Council on Federal Financial Relations should continue work to strengthen Federation Funding Agreements, through the inclusion of new practical clauses, to promote inclusion of people with disability and increased accessibility in mainstream services. The new practical clauses should detail mainstream service responsibilities and service delivery obligations for people with disability. Performance and outcome measures in relation to these mainstream services should be included in the Disability Supports Outcomes framework (see Action 23.1) and the Disability Outcomes Council (Action 20.5) should establish a mechanism to monitor and publicly report on the investment and performance of all governments in delivering inclusive and accessible mainstream services. This will be complemented by the recommended legislative reforms in Actions 2.1 and 2.3.

Implementation detail:

- States, territories, and the Commonwealth should:

    - Specify as part of a new IGA (20.1) funding shares based on the following principles:

        o The disability support system, including both the NDIS and foundational supports, is a shared responsibility for all levels of government, and financial contributions should be set to share costs and share proportionately the growth in costs over time.

        o Contributions by individual states and territories should reflect population shares.

- The Council on Federal Financial Relations (CFFR) should continue work to:

    - strengthen Federation Funding Agreements, through the inclusion of new practical clauses, to promote inclusion of people with disability and increased accessibility in mainstream services

2.5. The opinions of all people with disability are essential to governance structures

At a national level, people with disability are involved in planning and implementation of disability supports through the Board of the NDIA which now has a majority of Directors with a disability. There are also formal consultative arrangements through the NDIA's Independent Advisory Council (IAC), and ADS Advisory Council. The NDIA Board and IAC play critical legislated roles in the governance of the NDIS, while the ADS Advisory Council is responsible for providing advice on the progress of the ADS, including monitoring the ADS Targeted Action Plans (TAPs).

The IAC for the NDIS was originally established in 2013 under Part 3, Division1, and s143 of the *NDIS Act*. Its role is to, on its own initiative or following written request from the NDIA Board, provide advice to the NDIA Board in relation to how well the NDIA meets the needs of people with disability, including the way the NDIA performs in a series of functions, including the provision of reasonable and necessary supports, and supporting the independence and social and economic participation of people with disability. The NDIA describes the role of the IAC as, 'the voice of participants'.[2577] There are 12 members representing a wide range of disability and advocacy sectors supported by an independent consultant, and a special adviser.[2578] The Chair of the IAC is a member of the NDIA Board. The IAC is legislated to advise the NDIA Board only on its role in the administration of the NDIS. It does not have a broader remit to advise DSS or the NDIS Commission, or on broader matters relating to people with disability.

The NDIS Commission has recently changed its Industry and Sector Advisory Committees into a single Consultative Committee (the Committee). The Committee comprises NDIS participants, members of disability representative organisations, service providers and their representatives and is supported by three advisory groups: a participant, provider, and complaints advisory group.[2579]

The ADS Advisory Council was established in 2021 under a Terms of Reference to advise Australian governments and Ministers on the ADS's implementation. There are 11 members and two special advisers. The ADS Advisory Council is able to provide ongoing independent advice, feedback, and recommendations at a national level on the ADS, and is able to provide advice on other issues should it be agreed by governments, and raise emerging themes and issues raised in the disability community.[2580]

Practically, the roles of the IAC and the ADS Advisory Committee are separate, with the IAC focusing on its legislated remit, and the ADS Advisory Council operating within its Terms of Reference. There is some cross-over in personnel between the two bodies. The roles of each Council are described in more detail in Figure 170 below:

Figure 170: Roles and Responsibilities of the NDIS IAC and ADS Advisory Council

NDIS IAC	ADS Advisory Council
The NDIA Board requests the IAC provide advice. Along with self-identified priorities, an agreed work plan is developed. Advice is given to the NDIA Board in relation to how the NDIA: • performs its functions in relation to the Scheme • supports the independence and social and economic participation of people with disability • provides reasonable and necessary supports, including early intervention supports, for participants in the Scheme launch • enables people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports • facilitates the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability • promotes the provision of high quality and innovative supports to people with disability • raises community awareness of the issues that affect the social and economic participation of people with disability and helps with greater community inclusion of people with disability.	Provision of high-level advice to the Australian, state and territory Disability Ministers and governments on the implementation, monitoring, and evaluation of the ADS. This includes the provision of ongoing independent advice, feedback, and recommendations at a national level on the ADS, including on: • TAPs • Associated Plans • The Outcomes Framework • Periodic progress/implementation reports The ADS Advisory Council can explore and examine any component of these main elements, in order to develop their independent advice, feedback and recommendations. The ADS Advisory Council may provide advice to Disability Ministers and governments on other issues falling within scope of the ADS's outcome areas if agreed by all governments. The ADS Advisory Council may also discuss and raise emerging issues and themes raised in the disability community. The ADS Advisory Council will provide advice that may be used by governments as an input for reporting on Australia's obligations under the UNCRPD.

State and territory governments also have disability advisory and reference structures. These include:

• The ACT Disability Reference Group[2581]
• The Disability Council NSW[2582]
• Northern Territory Government Disability Advisory Committee[2583]
• Queensland Disability Advisory Council[2584]

- South Australian Government Disability Minister's Advisory Council and Disability Engagement Group[2585]
- Tasmanian Premier's Disability Advisory Council[2586]
- Victorian Disability Advisory Council[2587]
- Western Australian Ministerial Advisory Council on Disability[2588]

None of these bodies has a remit across the breadth of the national disability supports eco-system. This leaves gaps in coverage of the issues that affect people with disability and no single voice that can speak across all the elements of policy that affect the lives of people with disability.

2.5.1. The opinions of some people with disability are missing from the conversation about disability supports

We have heard clearly that there needs to be more opportunity across the governance system for a diversity of contributions from people with disability.

For example, the Australian Psychosocial Alliance emphasised the need to:

> *"Elevate the voice of people with lived experience of psychosocial disability in the redesign of the scheme." - Australian Psychosocial Alliance[2589]*

Children and Young People with Disability Australia raised the importance of the inclusion of experiences of children in governance structures:

> *"Ensure decisions made by the NDIA Executive and Board are informed by the views and experiences of children and young people with disability through:*
>
> *-designating NDIA board positions for young people with disability, mentored by more experienced board members*
>
> *the establishment of a NDIS Youth Advisory Council to provide advice to the NDIA board. The Youth Advisory Council could also provide its members with governance training and act as a pathway to NDIA board membership". - Children and Young People with Disability Australia[2590]*

The Early Childhood Intervention Best Practice Network wrote:

> *"Address the lack of representation on the NDIS Board by recruiting with Directors who have personal or professional experience with early childhood services. As almost 50% of NDIS participants are children, the Board should proportionally reflect this in time – with a target to have 25% representation by 2024 and 50% by 2025." - Early Childhood Intervention Best Practice Network[2591]*

The importance of the involvement of people with intellectual disability was raised by the Victorian Advocacy League for Individuals with Disability:

"'All levels of government should provide mechanisms to support the involvement of people with intellectual disability on Disability Advisory Committees" – VALID[2592]

We also received submissions from people with disability and their advocates describing the need for better understanding in governance structures and decision making of the needs of different groups.

Not all people with disability have opportunities to contribute perspectives through existing governance structures. Those with a primary disability of intellectual disability or autism - who make up approximately 50 per cent of all participants in the scheme,[2593] and people with disability with complex needs, do not always have the opportunity to provide input. Some people with disability, because they are non-verbal, or their use of communication methods other than language, or the fact that they (for example) live in supported independent living, rarely have opportunities to exercise their rights in communicating their views about how the NDIS works for them or how their supports can be improved.

The diverse needs of people with disability also intersect with other diverse characteristics and experiences which shape how people engage with the disability support ecosystem. This includes people with disability who are also First Nations people, women and girls, LGBTIQA+SB, and people who are culturally and linguistically diverse.

Facilitating contributions from people with a broader diversity of lived experiences of disability in governance structures will require new and innovative approaches. It will be important to work with people, their families and carers, and advocates to test strategies and methods to support more participation in governance structures. People with disability should be paid for undertaking these roles.

Where people with intellectual disability, those with complex communication needs, or people whose first language is not English are included in governance structures, there may be a need for these people to be supported so they can be active participants. This could include modifications to standard processes and ensuring any materials needed are accessible and understood.

Involving people with disability in matters that affect them is important to support true choice and control, facilitate the dignity of risk, shape appropriate safeguarding and ensure services and supports are designed and provided to people with disability in ways that suit them best.

The UNCRPD recognises the diversity of people with disabilities and takes measures to ensure the right to freedom of expression and opinion, and access to information.[2594] The UNCRPD also requires state parties to actively promote an environment where people with disability are supported to effectively and fully participate in public affairs and encouraged to do so (Article 29).[2595]

2.5.2. Ensuring the diverse opinions of people with lived experience of disability are at the centre of the disability support ecosystem

People with disability, their families, carers, allies and supporters, but especially people with disability, should be at the centre of a unified disability support ecosystem. To ensure this happens they should be deeply engaged in planning, policy, implementation, research, and evaluation across the unified disability support ecosystem.

Every four years, the Australian Government is required to report to the United Nations Committee on the Rights of Persons with Disabilities. The purpose of this report is to demonstrate what actions Australia has taken to protect, uphold, and promote the rights of people with disability. Prior to Committee review, Disability Representative Organisations (DROs) within Australia provide their views on Australia's progress to the Committee for their consideration through a Civil Society Report (a, 'shadow,' report).

The ADS Advisory Council provides Disability Ministers with, 'a concise Annual Report on the outcomes of the ADS's work,' and contributes to reporting processes under the ADS's reporting framework.[2596]

Both mechanisms have been critical in supporting opportunities for people with disability to comment on the performance of governments, both at a national and international level.

Under the new unified disability supports ecosystem, National Cabinet, through the Disability Reform Ministerial Council (DRMC), also needs to hear clearly the views of people with disability on the status and performance of the different elements of disability supports. This will be an integral part of the formal evaluative functions established under the Disability IGA.

We recommend a new body to represent the opinions of people with disability, families and carers to all governments and innovative approaches be explored to include the perspectives of all people with disability. This would complement a broader range of strategies to ensure the views of people with disability are included in decision making across the disability support ecosystem.

This new Disability Advisory Council could augment or, over time, replace the ADS Advisory Council.

2.5.3. Action and Implementation Details

20.3 National Cabinet should establish a new permanent Disability Advisory Council reflective of the diversity of people with lived experience of disability to advise Disability Reform Ministers.

The new Disability Advisory Council (DAC) could replace or augment Australia's Disability Strategy Advisory Council and should have a broad remit to advise governments across the disability support ecosystem. The new Council should be reflective of the diversity of people who have lived experience of disability. It should ensure people with disability are included in all aspects of planning, design, monitoring and evaluation of disability support. The DAC

should produce and publish a separate report providing disability community perspectives on the performance of governments drawing on, and accompanying, the Disability Outcomes Council's reports to National Cabinet through Disability Reform Ministerial Council (see Action 20.5). The National Disability Insurance Agency (NDIA) Independent Advisory Council (IAC) should continue to advise the NDIA Board, and the Chair of the IAC should be an ex-officio member of the new DAC. These measures should be complemented by other innovative and best practice strategies to hear the voices of people with disability, and ensure the full diversity of experiences and views are included.

Implementation detail:

- From 1 July 2025, the Australian Government and state and territory governments should create a Disability Advisory Council (the DAC). This will provide participants with a dedicated platform to provide their views and concerns, ensuring their perspectives are considered in decision-making processes. The Australian Government could commence the making of amendments to support changes to the ADS Advisory Council from 1 July 2025, depending on whether the DAC replaces or augments the ADS Advisory Council. The DAC should be supported by a Secretariat team at the Department of Social Services.
- The DAC's terms of reference should allow it to advise on any matter affecting all people with disability.
- The DAC should report annually to National Cabinet (through DRMC) on the state of the disability support ecosystem in Australia.
- DSS should also explore options to identify best practice in relation to alternative participatory methods such as citizens' juries. DSS should identify best practice for the inclusion of the broad range of perspectives of the disability community – including children and young people; people with intellectual and/or psychosocial disability and/or autism; and people who are non-verbal and how they should then be supported to be active participants.

2.6. Structural reform is needed to meet the culturally distinct needs of First Nations people with disability

First Nations people with disability have a distinct set of cultural needs which require tailored, purpose-built solutions. These need to be led by First Nations people with disability, facilitated by governance structures that prioritise and uphold the commitments made under the National Agreement on Closing the Gap (the National Agreement).

The National Agreement was formed on the belief that when First Nations people have a genuine say in the design and delivery of services that affect them, better life outcomes are achieved. This can only be achieved through structural reform[2597].

"…the life outcomes of Aboriginal and Torres Strait Islander people, and the success of the National Agreement, depends on governments changing the way they work…" - *Coalition of Peaks* [2598]

However, inconsistent training requirements, understandings and knowledge of First Nations concepts of disability, ways of being, cultural obligations, policy settings and Indigenous rights are undermining efforts to improve outcomes.

"Denial of, or limited access to, culturally safe and inclusive services and supports constitutes neglect of First Nations people with disability." – *Disability Royal Commission*[2599]

This results in real harm to First Nation Australians with disability.

2.6.1. Commitments to shared decision-making with First Nations people are positive but limited

In 2020, the National Agreement on Closing the Gap committed all Australian Governments to working in new ways to overcome the inequalities experiences by First Nations people. Closing the Gap identifies clear socio-economic outcomes underpinned by four Priority Reforms[2600]. All Australian Government Implementation Plans on Closing the Gap include a commitment to disability as a cross-cutting outcome area, across the four Priority Reforms and 17 socioeconomic targets, to mitigate the compounding effects of intersectional inequality.[2601]

The National Agreement (Priority Reform 1) commits governments to share decision-making authority with First Nations people through formal partnerships arrangements. The Strong Partnership Elements (Clause 32) of the National Agreement sets agreed standards for the operation of effective, accountable and representative partnerships.

In 2023, the NDIA jointly established the First Nations Advisory Council with the First Peoples Disability Network. Its focus is, however, limited to the NDIS. The First Nations Advisory Council consists of First Nations people with lived experience of disability, their representative and service organisations, alongside government representatives.[2602]

"Establishment of the First Nations Advisory Council has been a very positive step towards shared decision making, however this initiative is specific to the National Disability Insurance Scheme, and does not allow for broader systemic work or a focus on non-NDIS disability issues. FDPN is committed to ensuring that accountability of culturally inclusive, and Disability rights informed policies, programs and services exist throughout government and funded services. This needs a stand-alone governance structure…"– *First Peoples Disability Network*[2603]

2.6.2. Existing efforts to improve cultural safety lack accountability

The National Agreement (Priority Reform 3) sets out an ambitious agenda that commits all government organisations to enact change that improves accountability, supports the identification and elimination of racism and embeds cultural safety.

However, progress on meaningfully embedding Priority Reform 3 has been slow.

> *"Lack of progress on Priority Reform 3 is putting the other Priority Reforms and the (National) Agreement (on Closing the Gap) as a whole at risk." – Productivity Commission*[2604]

We need to do things differently and faster, through dedicated mechanisms that can appropriately identify and fill existing cultural capability and accountability gaps.[2605]

The Department of Social Services is currently supporting the First Peoples Disability Network, in partnership with Western Sydney University to develop a 'Cultural Model of Inclusion: Organisational Assessment Tool' (the Assessment Tool). The Assessment Tool aims to ensure services are culturally safe and inclusive for First Nations people with disability[2606]. The future implementation of the Assessment Tool could serve as an important step in government organisations and their funded service providers' journeys to improving disability-rights informed cultural safety.

> *"While the [Coalition of] Peaks have been encouraged by some progress of governments to embrace and implement the Priority Reforms in the National Agreement, overall efforts are too inconsistent and lack the necessary courage ". - Coalition of Peaks*[2607]

We have also recommended alternative commissioning of disability services which would be community led and culturally appropriate in remote communities (see Action 14.1). This would contribute to Closing the Gap by creating permanent jobs, training opportunities and careers in these communities and would need to governed and directed by communities, as governance mechanisms are strengthened through Closing the Gap. There are also opportunities for integrated service delivery across aged care and health in these communities.

However, what remains is a real gap in the governance of the disability ecosystem as a whole in order to hold itself to account for embedding the commitments made under the National Agreement's Priority Reforms across all aspects of institutions, systems, relevant legislation, policy and service delivery.

2.6.3. Centring First Nations people with disability in governance structures will improve the cultural safety of a unified disability ecosystem

The National Agreement defines cultural safety and makes clear that only First Nations people with disability can decide if culturally safety has been achieved:

> *"Cultural safety is about overcoming the power imbalances of places, people and policies that occur between the majority non-Indigenous position and the minority Aboriginal and Torres Strait Islander person so that there is no assault, challenge or denial of the Aboriginal and Torres Strait Islander person's identity, of who they are and what they need. Cultural safety is met through actions from the majority position*

which recognise, respect, and nurture the unique cultural identity of Aboriginal and Torres Strait Islander people. Only the Aboriginal and Torres Strait Islander person who is recipient of a service or interaction can determine whether it is culturally safe."
– National Agreement on Closing the Gap[2608]

The Disability Royal Commission found First Nations people with disability have a distinct cultural identity and distinct needs that inform their perception of what constitutes cultural safety. This means they are often forced to choose between disability accessible and culturally informed service delivery.[2609]

"First Nations people with disability have identified a need for existing culturally safe practices to meet their cultural and disability needs as a whole person, rather than providing for one but not the other." - Disability Royal Commission [2610]

The Disability Royal Commission also highlighted the need for governance reform due to the failure of siloed policy frameworks and service delivery models to uphold the cultural safety, rights and needs of First Nations people with disability. The recommended solution should elevate the voices of First Nations people with disability to drive policy reform from the ground up, ensuring culturally safety (see Disability Royal Commission Recommendation 9.10). We agree.

"But we don't just want it to be a steering committee that meets for a couple of hours and then something is signed off and before you know it, you've agreed to a strategy that perhaps hasn't been addressed adequately. It needs to continue to function. It needs to have authority, and it needs to be done in a co-designed way, which, in co-design, we mean by that equal power sharing, that is, about both parties learning from one another so that we can create the future we want." – Griffis, D., Public Hearing 25, Disability Royal Commission[2611]

Establishing shared decision-making and sector-specific accountability mechanisms will change the way that governments work with First Nations people with disability. Centring the commitments made by all governments under the National Agreement through a dedicated Schedule in a new Disability IGA will build the foundations for a culturally responsive, rights informed disability ecosystem (see Action 20.4).

Aged care has set up a First Nations Aged Care Commissioner to give a focus and authority to the needs of First Nations older people. The Panel is interested in such an approach.

2.6.4. Action and Implementation Details

Action 20.4 National Cabinet should develop a dedicated First Nations Schedule under the new Disability Intergovernmental Agreement to embed a First Nations Disability Forum and an independent sector-specific accountability mechanism.

This will fill accountability gaps and deliver on disability sector strengthening efforts and Priority Reforms under the National Agreement on Closing the Gap. The Schedule should be created in partnership with the relevant First Nations stakeholders and be led by the First Nations Disability Representative Organisation. The Schedule should establish and appropriately resource a First Nations Disability decision-making forum that adheres to the Strong Partnership Elements (Clause 32) of the National Agreement on Closing the Gap. The forum should drive community-led design, implementation and evaluation. The Schedule should also establish and appropriately resource an independent, sector-specific accountability mechanism, that aligns with approaches taken across the care and support sector, such as a First Nations Disability Commissioner, to support, monitor and report on mainstream agencies and institutions' ability to identify and eliminate racial ableism and embed and practice meaningful cultural safety across a unified disability ecosystem.

Implementation detail:

- The Department of Social Services (DSS) (and any other relevant agencies) should lead the development of a dedicated First Nations schedule under the proposed Intergovernmental Agreement (IGA) (see Action 20.1). The development of the schedule should be done in partnership with the relevant First Nations stakeholders, led by the First Nations Disability Representative Organisation.
- DSS should consider inclusions of the government's commitments through the United Nations Declaration on the Rights of Indigenous Peoples in the drafting of this schedule.
- DSS should provide funding (Clause 33 of the National Agreement on Closing the Gap) to the First Nations Disability Forum and other experts (if needed) to offer independent policy advice, meet independently of governments and engage with their communities. First Nations representatives should also be remunerated adequately for their time and contributions.
- DSS should ensure that the First Nations Disability Forum and First Nations Disability Commissioner have the appropriate resources and authority to fulfil their duties, protected by legislation (Clause 32 and Clause 67 of the National Agreement on Closing the Gap).

First Nations Disability Forum

- The Australian Government should ensure that the schedule provides the First Nations Disability Forum with the appropriate authority, resources and scope to:
  - Lead the design and delivery of a dedicated national strategy for First Nations people with disability (see Action 2.10)

- Review, design and make publicly accessible recommendations for improved process, policy and practice regarding cultural safety and accessibility for First Nations people with disability

- Review practice standards, mandatory training requirements, minimum standards, internal practice and legislation and provide recommendations that reflect best practice.

- Improve understandings of cultural models of disability and care

- The schedule should also set out the governance arrangements for First Nations Disability Forum including minimum standards for effective membership, meeting frequency, remuneration and secretariat support to reflect a new system-wide, holistic approach to First Nations disability policy and services.

• DSS should, in response to recommendations from the First Nations Disability Forum, where appropriate, facilitate changes to existing standards, rules and legislation

First Nations Disability Commissioner

• The Australian Government in considering an appropriate sector-specific accountability mechanism, could establish a First Nations Disability Commissioner with the appropriate independence, authority, scope and resources to:

- Drive sector-wide accountability and operationalisation of all four Priority Reforms outlined under the National Agreement on Closing the Gap

- Provide independent accountability for the implementation of the Disability Sector Strengthening Plan and forthcoming strategies for First Nations people with disability (including the proposed national strategy for First Nations people with disability (see Action 2.10) and forthcoming NDIA First Nations Strategy).

- Work in partnership with DSS and the National Indigenous Australians Agency to champion disability as a cross-cutting outcome across all Closing the Gap Targets and Priority Reforms

- Lead the development of a First Nations Anti-Racism and Ableism Framework that:

  o drives the development of mechanisms that proactively identify and seek to eliminate systemic discrimination
  o measures experiences of intersectional discrimination within the scheme and broader disability service system (incl. interactions with NDIA, NIAA

2.7.   Establishing a mechanism to independently monitor progress on inclusion and accessibility in Australia

At the apogee of current accountability mechanisms with accountability for ADS and the NDIS is the Disability Reform Ministers Council (DRMC). The Australian Government Minister for the NDIS chairs DRMC, and both DRMC and the Minister for the NDIS have key roles under the NDIS Act. Within the Australian Government the Minister for Social Services has responsibility for the ADS and is also a member of DRMC.

Other accountability measures are in place for the NDIS and ADS. These include the NDIA Board, the ADS Disability Advisory Council (see Section 2.5) and the NDIA Independent Advisory Council (see Section 2.6) However, these are largely stand-alone, their interoperability as a whole is unclear, and there is no coordinated or independent strategic assessment of government performance and investment in delivering outcomes for people with disability.

The federal Parliament's Joint Standing Committee on the NDIS has provided a very important independent accountability mechanism for the operation of the NDIS, since it was established very soon after the NDIS commenced in its trial phase in 2013. It comprises five members and five senators, drawn from all political parties and independents.

Since inception it has always operated on the basis of consensus, and it has completed many important reviews including:

• Accommodation for people with disabilities and the NDIS (2016)
• Market readiness for provision of services under the NDIS (2018)
• NDIS Planning (2020)
• Independent assessments (2021)
• Forecasting and future costs of the NDIS (2022)
• NDIS Workforce (2022).[2612]

The ADS has an Outcomes Framework, with system, population, and community attitudes measures. Of the 85 measures, baseline data is available for 47 launch measures. The First Annual Report of the Outcomes Framework released in February 2023 provided an overview of baseline

measures, with updated annual data and quarterly data, where available.[2613] The first implementation report for the period of the 2022-23 financial year will be available late 2023.[2614]

The NDIA also publishes an Annual Report, quarterly reports and occasional 'data insights'. A summary of the Annual Financial Sustainability Report and the letter to the Board from the Reviewing Actuary is provided in the Annual Report. However, these mechanisms are not sufficiently comprehensive, independent or have sufficient status. Submissions to the Review have expressed the importance of trust and the need for greater accountability.

The Joint Standing Committee reported the importance of trust in the operation of the NDIS:

> *"As a person centred and rights focused scheme, trust plays a crucial role in ensuring the effective operation of the NDIS.... Maintaining trust is also inherent in the management of financial sustainability of the scheme". - Joint Standing Committee on the NDIS*

To support independent accountability measures and reporting for the whole of the disability ecosystem, we are proposing a model based on the current reporting and accountability for Closing the Gap targets. This model is very similar to the role played by the former COAG Reform Council (see Box 101).

Box 101: Closing the Gap – Coalition of Peaks

The Coalition of Peaks was established in 2019 through a Partnership Agreement to work with all Australian Governments on matters affecting First Nations people. It is a representative body of more than 80 Aboriginal and Torres Strait Islander community controlled peak organisations. Peak organisations came together as an act of self-determination and to change the way Australian Governments work with Aboriginal and Torres Strait Islander people, organisations, and communities on Closing the Gap.

In July 2020 a National Agreement on Closing the Gap was established between parties. It includes a commitment to independent oversight and accountability. The Productivity Commission has developed and maintains a publicly accessible dashboard comprising data and associated supporting materials to inform reporting on Closing the Gap.

As part of the National Agreement, the Parties committed to systemic and structural transformation of mainstream government organisations to improve accountability and respond to the needs of Aboriginal and Torres Strait Islander people. While not specifically an action for the Coalition of Peaks, the Coalition has a key role in monitoring and influencing the progress of this – as with all actions across the partnership.

The role and operation of the former COAG Reform Council is outlined in Box 102 below.

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Box 102: Former COAG Reform Council (2006-2014)

COAG was the primary intergovernmental forum in Australia from 1992 to 2020.

In 2010, COAG established the COAG Reform Council as part of the arrangements for federal financial relations to assist COAG to drive its reform agenda.

The COAG Reform Council comprised a Chairman, Deputy Chairman, four Councilors and an Executive Councilor.

Independent of individual governments, the COAG Reform Council reported to COAG on reforms of national significance that require cooperative action by Australian governments, providing regular reports on the performance of governments in achieving the benchmarks set out in National Agreements and National Partnerships.

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We believe elements of both systems have important lessons for the monitoring and reporting on a unified disability ecosystem.

In considering the role and effectiveness of benchmarking arrangements through the COAG Reform Council, Mary Ann O'Loughlin, the former Executive Councillor and Head of Secretariat for the Council wrote:

> *"for the benchmarking arrangements to be effective they must be based on robust performance reporting frameworks, which are conceptually sound and supported by quality, comparable and timely performance information. Progress should also be assessed against clear milestones and outcomes and ambitious benchmarks. The aim is to encourage — even pressure — governments to take action in response to performance feedback". – Mary Ann O'Loughlin (former Executive Councillor and Head of Secretariat for the COAG Reform Council)*[2615]

The Productivity Commission held a joint Roundtable in 2010 with the Forum of Federations on Benchmarking in Federal Systems. In providing her dinner address, Helen Silver, then Secretary of the Victorian Department of Premier and Cabinet, stated:

> *"benchmarking and federalism promote policy rigour, encourage good government and help us provide better outcomes for citizens. They also share important practical similarities, in that they both can be incredibly difficult in practice, their value is not always well understood by key stakeholders, and neither is done for its own sake". – Helen Silver (former Secretary of Department of Premier and Cabinet – Victoria)*[2616]

However, it must be noted that while these comments point to the importance of transparently monitoring outcomes, close working relationships and strong sustained commitment from governments is required, as is an acknowledgement that significant results may take time.[2617]

The Disability Royal Commission observed, 'a key component of governance arrangements are structures for ongoing monitoring and reporting on key actions and outcomes. Despite recent improvements, gaps remain in reporting on outcomes for people with disability'.[2618]

We agree monitoring and reporting on key outcomes and actions of governments is critical in establishing public trust and confidence in a unified disability support ecosystem.

A new Disability Supports Outcomes Framework (see Action 23.1) will need to be developed in the light of the reforms we propose in this review. We also recommend a Disability Outcomes Council (DOC) monitor and report against performance, including this outcomes framework. This is consistent with the recommendations of the Disability Royal Commission that there is a need for an independent body with the ability for independent monitoring and reporting to support intergovernmental collaboration on the disability support ecosystem, and to build the trust of people with disability and the broader Australian community.

2.7.1. Action and Implementation Details

Action 20.5: National Cabinet should establish a Disability Outcomes Council to monitor and publicly report on the performance of all governments in meeting the outcomes, commitments and benchmarks outlined in the Disability Intergovernmental Agreement.

The Disability Outcomes Council (DOC) should be responsible for monitoring, reviewing, and reporting on the investment, outcomes, and benefits of all governments across the new disability support system against the new Disability Support Outcomes Framework (see Action 23.1). The DOC should draw on inputs from the Productivity Commission, given its role in reporting on government services and monitoring priority intergovernmental agreements, and from the proposed forecaster function (see Action 21.1). Reports should be made to National Cabinet through the Disability Reform Ministerial Council and published. This approach is modelled on the approach to Closing the Gap. The DOC should help embed a robust culture of monitoring and program evaluation across the disability support sector and agencies administering the scheme. Establishment of the DOC should be overseen by the NDIS Review Implementation Advisory Committee, which should then transition into the DOC (see Action 24.1). In establishing the DOC, consideration must be given to how the Committee will interact with the National Disability Commission recommended by the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, particularly in relation to reporting on improvements in inclusion.

Implementation detail:

- The Australian Government, in consultation with the states and territories, should establish the DOC, at the same time as the Disability Intergovernmental Agreement, similar to the former Council of Australian Governments Reform Council. DOC will assess performance of all parties to the Intergovernmental Agreement (IGA) (see Action 20.1)

a. The DOC should be included as a schedule within the IGA, which will help ensure its authority and effectiveness

b. The DOC should also consider data and analysis from the forecaster as to the sustainability, outcomes and benefits of the Disability Support Ecosystem

- The primary role of the DOC will be to assess the performance of all parties in meeting the outcomes, commitments, and performance benchmarks outlined in the IGA. This includes outcomes measures in the new Disability Support Outcomes Framework (see Action 23.1).

- Once the DOC is established:

  - It will assess performance of all Australian governments against commitments made in the IGA including against the Disability Supports Outcomes Framework.

  - Provide feedback on appropriateness of the measures included in the Disability Supports Outcomes Framework and make recommendations for improvement

  - The DOC should report to National Cabinet on an annual basis. The DOC's reports should be made public, similar to the report to Parliament on Closing the Gap.

3. Clarify accountability for sustainability and governance of the disability ecosystem

- As highlighted by this Review, everything is connected to everything else and so clarifying accountabilities and governance is an essential step in ensuring optimal outcomes for people with disability and that government investments are as effective and efficient as possible.

- The report by the Joint Committee on Community Affairs in 2007 on the then Commonwealth States Disability Agreement and the lack of clear accountability for outcomes highlights that this is a very long-standing issue.

- Central to this is clarifying responsibilities for sustainability because without the entire disability support ecosystem, including the NDIS, being sustainable, people with disability, their families, carers and the wider Australian community will not have trust and confidence that the supports they need now and in the future will be there.

3.1. There must be clarity in roles and decision making processes in the unified disability ecosystem.

The NDIS is a transformational reform. It is supported by unprecedented investment in disability supports and services by Australian governments. The sustainability of the NDIS is central to ongoing support from the Australian public and to ensure people with significant and permanent disability can access the supports and services needed for generations to come.

Sustainability of the NDIS has been a focus of all governments as responsibility is shared. The *NDIS Act* specifies that DRMC and the Minister for the NDIS should consider sustainability, and the NDIA

Board is responsible for managing, advising and reporting on scheme sustainability.[2619] However, the operationalisation of these arrangements in practice has lacked clarity.

People with disability, their families and carers, are not clear on who does what within the NDIS. The roles of Department of Social Services (DSS), the National Disability Insurance Agency (NDIA), and the NDIS Commission are overlapping in some contexts. There is a need for governments to clarify governance arrangements in relation to critical areas of the NDIS to best position it for its role in a broader unified ecosystem of supports. This includes who has ultimate responsibility and accountability for sustainability, market stewardship, pricing, regulation, commissioning and legislation.

A future unified disability support ecosystem must support governments to work together to manage NDIS costs, support key agencies to drive policies, regulation, and legislation that deliver high quality outcomes and sustained benefits for people with disability. This unified ecosystem must be represented and understood by people with disability. We propose a new governance structure for a unified disability support ecosystem, represented in Figure 168.

Recommendation 21: Clarify accountability for sustainability and governance of the disability ecosystem

🗐 Legislative change required

- 🗐 Action 21.1: <u>National Cabinet</u> should be accountable for the sustainability of the unified disability ecosystem, including the NDIS.
- 🗐 Action 21.2: <u>The Department of Social Services,</u> in consultation with state and territory governments, should review existing National Disability Insurance Agency operational guidelines to identify and prioritise opportunities to strengthen the National Disability Insurance Scheme Act 2013 and Rules.
- Action 21.3: The <u>Australian Government</u> should ensure that the Minister responsible for the NDIS remains a Cabinet Minister.
- 🗐 Action 21.4: The Australian Government should clarify roles of relevant agencies for administration market stewardship, pricing, policy, regulation, commissioning and legislation.

3.2.   Governments are responsible for the sustainability of the disability support ecosystem

The Australian, state and territory governments should have ultimate accountability for the sustainability of the broader disability ecosystem, including the NDIS. The NDIS is a significant investment by all governments on behalf of all Australians. Its sustainability is essential to maintain community support and ensure it can deliver for those who need it now and in the future.

The current accountability arrangements for the sustainability of the NDIS are not clear. Under the *NDIS Act*, DRMC and the Minister for the NDIS must have regard to its sustainability. Governments are also responsible for the NDIS Act and the scheme rules. However, the NDIA Board is

responsible for managing, advising and reporting on scheme sustainability.[2620] At the same time, all governments make decisions about disability supports outside the NDIS, and about access to mainstream supports which directly impact on NDIS sustainability.

We recommend sustainability should be considered at the whole of disability ecosystem level, including foundational and mainstream supports, and not just the NDIS. This will allow for a more holistic approach to sustainability, ensure that decision making is based on whole of system impacts, and ultimately ensure that supports are provided to all people with disability through the most efficient and effective system.

Sustainability of the NDIS is more than costs and should be viewed in a more holistic manner and encapsulate its benefits, outcomes and impacts on other systems. This will require more comprehensive reporting and assessment on the sustainability of the NDIS (see Chapter 7). More contestability around forecasting is also needed to improve reliability in the forecasting of future costs and benefits.

3.2.1. Accountability and sustainability of the NDIS roles should be operationalised more clearly

It is essential to clarify roles and responsibilities for the sustainability of the NDIS and the broader disability ecosystem through clearer operationalisation of the NDIS Act.

DRMC (reporting to National Cabinet) should continue to be accountable for policy and legislation for eligibility and entitlements framing the sustainability of the NDIS (see Action 21.2) and the broader ecosystem outside the NDIS.

In relation to the NDIS, NDIA processes should be codified in the NDIS Act and Rules rather than being managed through NDIA Operating Guidelines and through the considerable powers vested in the Chief Executive Officer of the NDIA, wherever it provides increased clarity and operational effectiveness (see Action 21.2). Further, where Operating Guidelines and delegations are being used to operationalise the NDIS, they must be congruent with the Act and Rules.

The NDIA Board is responsible for the governance of the NDIA and ultimately the NDIS and should continue to identify financing and sustainability issues relating to the NDIS. The NDIA Board should report all financing and sustainability issues on the NDIS to DRMC. This will form a major input into DRMC's assessment of the overall sustainability of the broader disability ecosystem.

This would align responsibilities with the new Disability IGA (Action 20.1) which governs the broader disability ecosystem and not just the NDIS.

3.2.2. NDIS sustainability should be assessed in the context of the entire disability ecosystem

Sustainability of the NDIS is more than costs and should be viewed in a more holistic manner and encapsulate the benefits, outcomes and impacts on other systems. This will require more comprehensive reporting and assessment on the sustainability of the NDIS, and incorporate more contestability and reliability in the forecasting of future costs and benefits.

DRMC should appoint an independent forecaster to review and provide advice to the Council and then National Cabinet on total disability spending and projections, including NDIS scheme expenditure and projections, and the financial sustainability of the disability support ecosystem. The Annual Financial Sustainability Report (AFSR) from the NDIA Scheme Actuary, and independent review of the AFSR by the Reviewing Actuary, should be major sources of information supporting the forecasts of overall scheme sustainability. In addition to building on the Scheme Actuary's forecasts, the forecaster should also consider data from the Productivity Commission (who oversees priority IGAs) and the Australian Institute of Health and Welfare, including the National Disability Data Asset.

The forecaster function will ensure that all governments, who are ultimately responsible for the sustainability of the disability ecosystem, are able to receive independent assurance and advice on the NDIS and disability expenditure and projections and gain insights on the interaction between them, which will assist with the ongoing effective and sustainable management of the disability ecosystem.

The forecaster should also provide data and analysis to the DOC (Action 20.5) as part of its role to monitor, review and report on the investment, outcomes and benefits of the disability ecosystem.

Assessing NDIS sustainability as part of the entire disability ecosystem will deliver key insights, such as the level of support the scheme provides, outcomes, the balance between the NDIS and foundational systems, and data on foundational supports most required by people with disability.

3.2.3. NDIS forecasts should be continuously improved

The primary method to assess the scheme's sustainability is through the Scheme Actuary's Annual Financial Sustainability Report (AFSR), which also assesses risks to sustainability, and provides estimates of future costs of the NDIS.[2621] Actuarial forecasts, on which the AFSR is based, seek to use past trends to predict the future. This works well in a mature scheme, but not well when experience is still emerging.

Under the NDIS Act, the annual forecasts by the Scheme Actuary are reviewed by an independent Reviewing Actuary under section 180E.[2622] Since the commencement of the NDIS in 2013 the Reviewing Actuary has been the Australian Government Actuary. While these reviews have found the AFSR projection to be 'not unreasonable', the immaturity of the NDIS and its dynamic operating environment have led to regular significant revisions to NDIS cost projections. This has meant that NDIS costs have been unpredictable and could potentially undermine government and public confidence in the scheme.

Improving the accuracy of NDIS projections would instil greater confidence in the predictability of the scheme and its costs and reassure governments, taxpayers, participants and their families on its enduring nature.

The Scheme Actuary should develop different forecasting modelling approaches to improve the accuracy of NDIS projections. Taylor Fry's 2021 Review of NDIA's actuarial forecast model and drivers of Scheme costs found that while the current AFSR projection model is largely fit for purpose, it may have contributed to an underestimation of scheme projections in past AFSRs.[2623] Taylor Fry concluded that a projection based on an alternative model dividing cohorts by the amount of support they received may have helped improve projections.[2624]

It is also important for forecasts to understand potential additional demand for the scheme, as well as a range of other factors impinging on scheme sustainability (see Chapter 7). We also recommend the NDIA formalise the process to improve the contestability, robustness and consistency of forecast and projected scheme expenditure. This includes consulting more regularly with the Commonwealth Treasury on broader macro-economic parameters that impact the NDIS (such as wages and inflation) and micro economic parameters of the care sector. DSS should also establish a process for testing the assumptions used in the AFSR model, such as maintaining independent models to validate the AFSR to support greater contestability and transparency.

3.2.4. Sustainability of the NDIS should include costs, benefits and net fiscal impact on other schemes

Sustainability is more than costs - it is also about outcomes. Currently, the NDIS Annual Financial Sustainability Report (AFSR) produced by the Scheme Actuary predominately assesses scheme sustainability through a lens of financial costs rather than the benefits and outcomes achieved by the NDIS.

We consider the AFSR should report on the overall sustainability of the NDIS, by measuring costs, benefits and net fiscal impact on other schemes and programs (including the disability ecosystem).

The 2011 Productivity Commission Inquiry identified reduced costs in other government services as one of the intended benefits of the NDIS.[2625] However, the AFSR does not currently consider how the NDIS interacts with other government systems, including where the scheme replaces other government programs and services. The Scheme Actuary should estimate the net system costs and benefits of the NDIS. In the 2020-21 AFSR, the Scheme Actuary identified that further work is needed to monitor and understand the impact of supports and their effectiveness to improve participant outcomes.[2626] The Scheme Actuary should continue improving the measurement of NDIS benefits and incorporate it as part of AFSR reporting.

As part of this Review, Taylor Fry was commissioned to estimate scheme benefits as well as costs. Its report, NDIS Review – Costs, benefits and frameworks found evidence the scheme was improving outcomes and benefits for NDIS participants and carers in some key areas.[2627] Taylor Fry found measurable improvements in life satisfaction and evidence of reduced hospital costs suggesting better health outcomes for these participants.

Taylor Fry's net benefits estimation used available data and selected methodologies to estimate benefits provided by the NDIS but they also noted their estimate of benefits was most likely an underestimate due to data limitations. Taylor Fry could not measure the cost substitution benefits

of the scheme, for example through replacing previous household and charitable spending, which in Taylor Fry's view were likely to be substantial.

Estimates were also limited to a point in time and largely excluded the scheme's investment principles, which is that upfront supports will generate later benefits. One of the scheme's main benefits is the insurance and reduction to risk it offers all Australians, which was not covered in Taylor Fry's report.

It is clear that measuring the benefits of the NDIS at this point is not possible because of significant data limitations and that there are also challenges regarding assumptions. Taylor Fry's analysis clearly demonstrates a need for improved measurement of the benefits of the NDIS.

All Governments have taken a greater interest in supporting scheme sustainability while ensuring it remains demand driven. In April 2023, governments through National Cabinet committed to moderate scheme growth by agreeing to a new NDIS Financial Sustainability Framework. The framework includes an annual growth target in total costs of the NDIS of no more than 8 per cent by 1 July 2026 with further moderation of growth as it matures.

3.2.5. Action and Implementation Details

Action 21.1: National Cabinet should be accountable for the sustainability for the whole unified disability ecosystem, including the NDIS.

Consistent with National Cabinet's focus on the sustainability of the NDIS in 2023, this accountability should extend to the whole disability ecosystem. The Disability Reform Ministerial Council (DRMC) should support National Cabinet with an ongoing role for prioritising and agreeing disability policy reform directions. DRMC should appoint a forecaster to review and provide advice to National Cabinet on total disability spending and projections, including NDIS scheme expenditure and projections, and the financial sustainability of the disability ecosystem, including the NDIS. The approach to assessing the sustainability of the disability ecosystem should acknowledge the benefits, as well as costs, of disability supports.

In relation to accountability for the sustainability of the NDIS, responsibilities within the existing legislation should be operationalised more clearly. Specifically, DRMC (reporting to National Cabinet) should continue to be accountable for the policy and legislation for eligibility and entitlements framing the sustainability of the NDIS (see also Action 21.2) and the broader ecosystem outside the NDIS. The NDIA Board should remain responsible for sustainability of the NDIS within that framework and broader ecosystem. The NDIA Board should then continue to identify and report on NDIS financing and sustainability issues to Disability Reform Ministers. This will be a major input into the assessment of the overall sustainability of the disability ecosystem.

The Annual Financial Sustainability Report (AFSR) produced by the Scheme Actuary should report on the overall sustainability of the NDIS, by measuring costs, benefits and net fiscal

impact on other schemes and programs (including the disability ecosystem). The Scheme Actuary should also develop different forecasting models, including for specific cohorts, to improve the accuracy of NDIS projections. The AFSR should be a major source of information supporting the forecasts of overall scheme sustainability.

Implementation detail:

National Cabinet should, as part of the new IGA, commit to joint accountability for the sustainability of the unified disability ecosystem. To support this shared accountability, DRMC should appoint a forecaster to review and provide advice on sustainability.

The NDIA should:

- ensure the NDIS Annual Financial Sustainability Report considers financial sustainability holistically by considering whole of system costs and benefits including the efficiency of the scheme in delivering outcomes
- commission an independent review of the methodology underlying the Scheme Actuary's forecasting model every three years or before the Intergenerational Report, and provide an update to Disability Reform Ministers and the Treasury to inform the Intergenerational Report
- develop different forecasting models to improve the accuracy of projections and supplement the main methodology underlying the Scheme Actuary's forecasting.

The Australian Government should commence improvements on measuring scheme benefits by evaluating established methods, commissioning research and enhancing datasets, including linked administrative data (see Action 23.4).

3.3. The Australian Government should strengthen legislation and rules instead of relying on operational guidance for the governance of the NDIS.

3.3.1. NDIS decision making needs to be consistent and transparent

The Review has had consistent feedback from people with disability, their families and carers, about a lack of consistency and transparency in decision making about scheme access, and reasonable and necessary supports.

Many submissions to this Review requested clarity and consistency. For example:

> *"Please explicitly state what is not allowed instead of tiptoeing around it. Have much clearer guidelines and even a process for planners to enquire. There is no consistency amongst planners either indicating they do not have clear guidelines either." – Participant [2628]*

> *"The NDIS/NDIS are constantly changing the 'ballpark' on the decisions they are making. I want honesty and transparency." – Carer [2629]*

The Hopkins Centre, Law Futures Centre and Policy Innovation Hub, in undertaking their research project *Adjudicating Rights for a Sustainable National Disability Insurance Scheme* identified that there is:

> *"A lack of transparency by the NDIA about how decisions are made and a lack of explanation for decisions is contrary to what is required of administrative justice." – Hopkins Centre – Law Futures Centre and Policy Innovation Hub* [2630]

The Joint Standing Committee inquiry into the Capability and Culture of the NDIS has noted in their interim report (2023) a need for transparency in decision making, in particular recommending that

> *"...the government invest in training NDIA staff and updating systems to improve the quality and transparency of decision making, and to ensure that decisions consistently meet the requirements of the NDIS Act, so participants do not have to tell their stories again and again to multiple people." – Joint Standing Committee on the NDIS* [2631]

3.3.2. Issues with Operational Guidelines

We are aware of particular concerns that the NDIA Operating Guidelines have not always been consistent with the *NDIS Act* and Rules. The Administrative Appeals Tribunal (AAT) has ruled on a series of matters that indicate issues with operational guidelines. For example, in SCHW and National Disability Insurance Agency {2021} AATA 591 (12 March 2021), Tribunal Deputy President JW Constance identified that, in the view of the AAT, the provisions of the Assistance Animal Operational Guideline were internally inconsistent and not consistent with the objectives and principles of the NDIS Act.

In the 2019 Review of the *National Disability Insurance Scheme 2013* by David Tune (the Tune Review) a key findings was that 'the legislative framework for the NDIS and the NDIA administrative practices need to enshrine transparency as a principle underpinning all their engagement with people with disability'.[2632]

We believe that people with disability must have certainty and clarity in relation to NDIA decision-making, including the basis on which decisions are made.

The establishment of the 'Our Guidelines' webpage by the NDIA and the work being undertaken to update all guidelines for clarity and simplicity is welcome. We understand that the introduction of the NDIA's new ICT business system, PACE, will also make it easier for NDIA delegates to reference relevant rules and guidelines when making decisions. However, some submissions highlighted the importance of ongoing work to increase clarity in decision making:

> *"It is acknowledged that the NDIA has been progressing work on updating guidelines and documents to ensure that these are written in plain and Easy English and use less jargon; the NDIA has also produced resources on the types of supports that are funded, which include examples, to provide information about what is considered 'reasonable and necessary'. However, continued work in this area is required" – Australian Public Advocates and Guardians* [2633]

One way to achieve greater transparency is to ensure that key policy parameters for the administration of the NDIS are elevated into the NDIS Act and Rules. This would provide clarity and certainty to people with disability about how the NDIS operates. At the same time, it would establish a transparent process for policy changes in the administration of the NDIS. If the NDIA believes that the Act or the Rules need to change – for example, in response to consideration of the implications of a decision of the Federal Court - then rather than just seeking to modify them through internal policy changes, the NDIA would need to raise their proposals with the Minister for the NDIS and Disability Reform Ministers. This would allow an opportunity for open consideration by governments with input from people with disability into any potential changes to legislation or rules.

Given that all the major Rules affecting participant eligibility and entitlements are Category A Rules under s209 of the NDIS Act – meaning they can only be changed with the unanimous agreement of all states and territories – and any legislative changes would require support from both the House of Representatives and the Senate, there are considerable safeguards in this approach for participants.

We believe this would create transparency and over time build trust and confidence in the scheme and its management by the NDIA. It will also support scheme sustainability as the NDIA could only operate the scheme in accordance with legislation.

3.3.3. The Role of the Administrative Appeals Tribunal (AAT)

One aim of raising operational guideline to legislation and rules is to reduce the need for participants to rely on the AAT to get fair outcomes. Part 6 of the NDIS Act sets out the process for review of decisions made by the NDIA. This part of the Act outlines reviewable decisions and decision makers (section 99), how a review of reviewable decisions may be sought internally (section 100), and the avenue of applications to the Administrative Appeals Tribunal should the individual not be satisfied with internal review (s103).

The NDIA reports that in the June 2023 quarter, 8,355 requests for a reviewable decision were made.[2634] Of the 7,680 requests for a reviewable decision that were closed in the June 2023 quarter:

- 4,127 confirmed the NDIA's decision
- 1,262 requests were withdrawn
- 2,291 decisions were amended or set aside.[2635]

Since the commencement of the NDIS:

- There have been 16,343 Administrative Appeals Tribunal cases
- Of these cases, 13,428 cases have been closed (82 per cent)
- Of those 13,428 closed cases:

  - 13,118 were resolved by the time of hearing (98 per cent)

  - 310 have gone to hearing and received a substantive decision (2 per cent).

As at the June 2023 quarter, 2,915 AAT cases remained open (18 per cent of the total cases since NDIS commencement).[2636]

We are concerned at the number of AAT matters resolved by the time of hearing, indicating that these cases could have been settled at an earlier time. We have been advised by people with disability, their families and carers that the experiences of the AAT process and the NDIA's approach to engaging with matters have caused frustration and distress.

The NDIA reports that of the cases no longer before the AAT, around 66 per cent were resolved by agreement. Dismissal by the AAT or withdrawal by the applicant occurred in 29 per cent of those cases. Just two per cent progressed to a substantive hearing.[2637]

We welcome developments throughout 2023 in relation to the release of the NDIA's Model Litigant Guidelines and measures to improve early resolution of disputes including the Independent Expert Review panel. However, we also note the spending by the NDIA on external lawyers in 2022-23 was $72 million with $67 million – 92 per cent - of that expenditure on the AAT.[2638]

We have also received a number of submissions that reflect the impact of the process on people with disability and raise questions about the NDIA's approach. We note similar issues were identified by the JSC in their NDIS Planning Final Report in December 2020.[2639]

The Public Interest Advocacy Centre (PIAC) told the Review that the:

> *"Experience in representing applicants in AAT disputes is that the NDIA continue to engage in AAT disputes in an unnecessarily protracted, adversarial, and costly manner" – PIAC* [2640]

Connections Case Management submitted that:

> *"Review of decisions and AAT process is almost part of the planning process now. Once a plan has been given via the AAT, it should not be able to be slashed again the next year...Trauma and distress to participants and families because of the review process...Insufficient supports to participants due to plans being cut and them being too scared to go through the process of AAT and advocate organisations having no capacity to help them. Often, they are without family support, and it is too much for them to go alone, and support coordinators are not allowed to help with the process."*
> *- Connections Case Management* [2641]

Some submitters reflected on the human rights concerns with the AAT approach:

> *"The UNCRPD is not followed by the NDIS and this is evident in some of the cases and decisions of the AAT. For example, very few Aboriginal or Torres Strait Islander people are applicants of AAT cases. In addition, AAT decisions often reflect a deficit model of disability rather than a social model (which is underpinned by the UNCRPD)" – Advocacy WA* [2642]

A submission from four members of the Independent Expert Review (IER), a trial independent process established by the NDIA in late 2022 to address the backlog of 5,000 AAT cases, made a

number of suggestions to address the overall architecture of decision-making and review in the NDIS. This included the need to establish an ongoing independent review process at an intermediate level between an internal NDIS review and the AAT.

Independent administrative review should continue to play an important role in testing the fairness and appropriateness of decisions made by the NDIA. However, it is critical that the NDIA follows both its own guidelines on its obligations as a model litigant and the Australian Government *Legal Services Directions 2017* which require, '…the Commonwealth and Commonwealth agencies to behave as model litigants in the conduct of litigation.' These obligations include (among other things) acting honestly and fairly in handling claims and litigation – for example, dealing with claims promptly and not causing unnecessary delay, acting consistently and paying legitimate claims without litigation where it is clear that the liability is at least as much as the amount to be paid.[2643]

We believe that a review of existing operational guidelines and elevation of key decision policy to legislation will help to build trust with people with disability by increasing transparency and consistency of decision making.

3.3.4. Action and Implementation Details

Action 21.2: The Department of Social Services, in consultation with state and territory governments, should review existing National Disability Insurance Agency operational guidelines to identify and prioritise opportunities to strengthen the National Disability Insurance Scheme Act 2013 and Rules.

This should elevate key policy parameters to legislation and rules where relevant, instead of relying on operational guidelines and informal guidance within the National Disability Insurance Agency (NDIA) to ensure transparent governance of the NDIS. Key elements of the scheme's operations, including sustainability and reasonable and necessary supports, should be codified in legislation and rules as much as is practical. Where the NDIA continues to rely on Operational Guidelines, they must be aligned with the principles in the legislation.

Implementation detail:

- From 1 January 2024, DSS, working with the NDIA, should review existing operational guidance and identify and prioritise opportunities to strengthen the Act and associated Rules.
- By 2025, DSS should commence the process of implementing the identified amendments. This approach will ensure that the NDIS is governed by a robust and clear framework, benefiting all those involved.
- Once amendments are made, DSS should translate the *NDIS Act 2013* into alternate formats including Easy English within 12 months.

3.4.   A Cabinet Minister to support the delivery of a unified disability support ecosystem

The size of the disability sector in Australia is significant.

- Investment in disability supports and services across Australia is substantial, supporting one in five Australians live with disability.[2644]
- In 2021-22 there were around 325,000 workers supporting NDIS participants, their families and carers.[2645]
- Approximately 11 per cent of the population provides unpaid care to people with disability and older Australians.[2646]

The responsibility for disability policy is currently shared by two Cabinet Ministers. As shown in Figure 171, the Minister for Social Services has responsibility for all disability policy excluding the NDIS (for example, the ADS) while the Minister for the NDIS and Minister for Government Services is responsible for the NDIS and associated agencies (for example, the NDIA).

Figure 171: Ministerial Offices, departments of state and guide to responsibilities at 31 May 2023[2647]

Role	Office(s)	Guide to responsibilities
Cabinet Minister	Minister for Social Services	All except Housing, Homelessness, the National Disability Insurance Scheme and Government Services (including NDIA and Services Australia)
Cabinet Minister	Minister for the National Disability Insurance Scheme Minister for Government Services	The National Disability Insurance Scheme and Government Services (including NDIA and Services Australia)

Recently, the Disability Royal Commission recommended a Minister for Disability Inclusion, responsible for disability inclusion strategy, policies and programs that are currently under the remit of the DSS.

Over time there should be opportunities for greater coordination across the disability support ecosystem and care economy (see Action 21.4), but the size and complexity of the NDIS and the scale and time required to implement the reforms recommended by this Review, as set out in Recommendations 24, 25 and 26, mean that the NDIS should continue to have its own Cabinet-level Minister.

The NDIS is not only one of the largest and fastest growing parts of government but it will only be sustainable if it works in concert with other portfolios like Health and Aged Care, Education Skills and Employment, Early Childhood and Housing which contribute to outcomes for people with

disability. In a unified disability support ecosystem, it is critical that the interests of people with disability are represented at the highest level of decision making to ensure a joined-up approach to upholding their rights and coordinating the supports on which they rely.

3.4.1. Action and Implementation Details

Action 21.3: The Australian Government should ensure that the Minister responsible for the NDIS remains a Cabinet Minister

Given the scale of the NDIS, this should facilitate the fiscal, policy and delivery impacts of the NDIS being factored into relevant government decision-making, including across the care economy.

3.5. People with disability need policy cohesion to drive a unified disability system

There is currently a lack of clarity of roles and responsibilities across the system, resulting in unnecessarily poor outcomes for people with disability.

3.5.1. Clear roles and resourcing for Australian Government NDIS agencies

Within the Australian Government, the relationships between the NDIA, NDIS Quality and Safeguards Commission (NDIS Commission) and Department of Social Services (DSS) are blurred, with different policies and programs sitting in different agencies. This has contributed to poorer outcomes for people with disability.

In particular, there is a lack of clarity about who leads and supports important functions including market stewardship, policy, regulation, and commissioning for different functions. For example, the NDIA, the NDIS Commission, and DSS all have roles in NDIS markets, but which agency sets policies and facilitates effectively operating markets is unclear. Some submissions highlighted the impacts of this lack of clarity.

> *"Many roles under the NDIS can be confusing for participants, supporters and providers alike. For instance, the difference between the roles and functions of the National Disability Insurance Agency (NDIA) and the NDIS Commission is not well understood. Clear accessible explanatory information must be made available to participants to avoid unnecessary confusion and anxiety." – People with Disability Australia* [2648]

Clarity in roles should be supported by structures and resourcing to set agencies up for success. As noted, the Australian Government is solely responsible for the cost of administering the NDIS. Resourcing for the NDIA to date has been set well below the rate suggested by the Productivity Commission. This has in turn impacted the NDIA's ability to administer the scheme effectively.

One of the major challenges that the NDIA has faced, in the past, has been staff caps. At times this has restricted the NDIA's capacity and capability to undertake its role as administrator of the NDIS effectively.[2649] This has extended to the NDIA's Partners in the Community Program. The Productivity Commission envisaged Local Area Coordinators as, 'broad services, including individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area.'[2650] The NDIA staff cap resulted in Local Area Coordinators becoming planners, meaning vital efforts to build social and community capital have not been undertaken. There has also not been sufficient investment in the determination of reasonable and necessary supports, even though this is the bedrock of an equitable and sustainable scheme (see Chapter 2). Given the very significant reform agenda ahead, the Agency will need ongoing funding certainty to meet the costs of administering the NDIS effectively.

The NDIS Commission has also experienced resourcing issues since its establishment that have impacted their ability to fully deliver their remit. The new National Disability Supports Quality and Safeguards Commission will also need to be appropriately resourced to undertake its expanded role and have ongoing funding certainty to attract and retain high quality staff (see Action 19.3).

3.5.2. Commissioning arrangements will also need to support a unified disability ecosystem

The commissioning of services and supports will be critical to the effective functioning of the new unified disability supports ecosystem. Existing commissioning arrangements of services (for example, Partners in the Community, and Information, Linkages and Capacity Building program) occur across the NDIA and the Department of Social Services, but the commissioning approaches are all based on purchaser provider type arrangements, when people with disability may be better served through relational contracting style arrangements which have better feedback loops and a more engaged approach to measuring outcomes.[2651]

We therefore support the significant upskilling of commissioning capabilities in the NDIA and DSS, including clarification of the roles of departments and agencies in the commissioning of services and supports for the future. These arrangements should be linked to a relevant lead agency and be supported by engagement and advice from other relevant parties.

We suggest:

- The NDIA should be the lead partner of commissioning the proposed navigation function (see Action 4.3)
- The NDIA, in partnership with First Nations communities, should commence the roll out of alternative commissioning arrangements for both First Nations and remote communities (see Action 14.1)
- The NDIA should be responsible for establishing provider panels (commencing with allied health supports) in small/medium rural towns, or where persistent supply gaps exist (see Action 13.2)
- The Department of Social Services should continue work with the Department of Health and Ageing, the NDIA, and the new National Disability Supports Quality and Safeguards

Commission to identify opportunities across the care and support system to support more integrated and broader approaches to commissioning.

3.5.3. Improving coherence across the care and support economy

In May 2023, the Australian Government initiated a process to develop a National Strategy for the Care and Support Economy. The development of the Strategy is recognition of the need to ensure sustainable, high-quality care and support delivered by a strong workforce for Australians into the future. The Strategy focuses holistically on improving the quality of care and support jobs within four key sectors – early childhood education and care, disability support, veterans' care and aged care.[2652]

Our recommendations align with this agenda. The transition of the responsibility for pricing advice to the Independent Health and Aged Care Pricing Authority (IHACPA) (see Action 9.5), an integrated approach to workforce development for the care and support sector (see Action 15.3), and the streamlining and harmonisation of worker screening for care and support workers (see Action 17.5) are examples.

We believe this work should continue given the large populations depending on these sectors, the crossover of providers and workers, and the significant investment involved.

3.5.4. Action and Implementation Details

Action 21.4: The Australian Government should clarify roles of relevant agencies for market stewardship, pricing, policy, regulation, commissioning and legislation.

This should include the Department of Social Services, the future National Disability Supports Quality and Safeguards Commission, the National Disability Insurance Agency and the Independent Health and Aged Care Pricing Authority. Over time, government should consider opportunities to more closely coordinate the administration and planning of disability supports, workforce and safeguard mechanisms with other programs and regulation across the care and support systems. This should focus on driving improvements in efficiency, effectiveness and outcomes in areas such as quality and safeguarding, research and innovation, market stewardship and assessment of function and support needs.

Implementation detail:

- The Australian Government should clarify roles and responsibilities across the Department of Social Services, the National Disability Insurance Agency, the National Disability Supports Quality and Safeguards Commission and the IHACPA to support the effective functioning of the disability ecosystem, to reduce duplication, and drive efficiencies.
- To give effect to the new disability eco-system, there should be clear and strengthened responsibilities for commissioning of supports and services:

- The NDIA should be the lead partner of commissioning of the navigation function (see Action 4.3)

- The NDIA, in partnership with First Nations communities, should commence the roll out of alternative commissioning arrangements for both First Nations and remote communities (see Action 14.1)

- The NDIA should be responsible for establishing provider panels (commencing with allied health supports) in small/medium rural towns, or where persistent supply gaps exist (see Action 13.2)

- DSS, in consultation with the Department of Health, the Department of Education, and States and Territories, should have responsibility for commissioning foundation supports (see Action 1.1).

- The Australian Government should identify opportunities to more closely coordinate the administration of disability supports with similar sectors. This should include:

  - Mapping of similarities and differences across quality and safeguarding, research and innovation, market stewardship, workforce, and assessment of function and support needs across sectors

  - Identifying opportunities through shared activities to amplify and protect the human rights of those who access like sectors.

4. Embed a highly skilled, person-centred, disability-aware culture across all disability agencies and governments

4.1. People with disability should have confidence that government agencies and departments within the unified disability support ecosystem operate in skilled, person centred, and disability-aware ways

- The personnel of key disability departments and agencies and their values and culture are key to the realisation of our vision of a unified disability support ecosystem.

- All Australian Governments need to work together in new and deeper ways. Staff will need to be properly equipped to deliver complex and innovative reforms across an already complex system, which has experienced very significant changes in recent years.

- Some people with disability have advised us of sub-optimal interactions with the NDIA and its partners. These reports have included experiences of a lack of trauma informed practice, disability awareness and human rights approaches.

- In a unified disability support ecosystem, all personnel operating in disability policy, regulation and operations must be able to interact appropriately with people with disability, their families and carers. They must have strong culture and capability to be influential

across mainstream and foundational supports. The workforces of all Australian governments engaging in disability policy, regulation, and operations must have the right attitudes and skills to support the inclusion of people with disability in all aspects of work, social, and community life.

- Capability reviews are one method to improve the culture of agencies.
- The NDIA commitment to people with disability and improving their experience should be reflected by a strengthened Participant Service Guarantee that adds quality measures to existing performance metrics based on timeframes.

Recommendation 22: Embed a highly skilled, person-centred, disability aware culture across all disability agencies and governments

⬜ Legislative change required

- Action 22.1: When undertaking capability reviews, the Australian Public Service Commission should have regard to the capacity, capability and culture of the National Disability Insurance Agency, National Disability Supports Quality and Safeguards Commission, and Department of Social Services to deliver relevant reforms.
- Action 22.2: The National Disability Insurance Agency and the new National Disability Supports Quality and Safeguards Commission should publish biennial culture and capability plans every two years, supported by independent audits and staff, participant and stakeholder surveys.
- 📄 Action 22.3: The Australian Government should re-design the Participant Service Guarantee to prioritise high quality, transparent and efficient decisions and improved participant experience.
- Action 22.4: The Disability Reform Ministerial Council should agree measurable culture and capability outcomes as part of new funding arrangements.

4.2. People with disability need high performing agencies and staff with specific skills to deliver disability supports and services in a unified disability system

The issue of trust was central to our review. Our terms of reference outlined an objective to restore trust, confidence and pride in the NDIS. The Joint Standing Committee (JSC) has also commented on the importance of trust in the operation of the NDIS.

> *"As a person centred and rights focused scheme, trust plays a crucial role in ensuring the effective operation of the NDIS.... Maintaining trust is also inherent in the management of financial sustainability of the scheme". - Joint Standing Committee on the NDIS* [2653]

During the period of our review the JSC conducted a review into the capability and culture of the NDIA. We have heard views, particularly from people with disability and carers, which align with those heard by the JSC.

We have heard about a breakdown of trust between participants and the NDIA. These issues include a lack of understanding about disabilities, adversarial approaches, inconsistent advice, and an absence of trauma informed practice.

The Joint Standing Committee's interim report states that:

> *"...the committee has heard...that there are significant issues with the capability and culture of the NDIA, which are having a serious impact on delivery of the NDIS and on people trying to access information, support, and service from the agency." - Joint Standing Committee on the NDIS* [2654]

Examples of submissions we received that support this JSC finding include:

> *"After each planning meeting I am left in tears and feel extremely stressed. The planners are generally rude, lack empathy and have limited (if any) understanding of disability. Please employ people with lived experience of disability. Please adequately train staff." – Carer* [2655]

> *"The NDIS should consider alternative application pathways for people from disadvantaged backgrounds and communities that are appropriate for those communities. It is often hard to translate things that are assumed knowledge in our community into something an NDIS person with no real experience with my community would understand." - Participant and carer* [2656]

> *"It would be helpful to have trained NDIA staff who understand what the person with a disability is applying for, there seems to be a lacking of appropriately trained NDIA staff." - Person with disability* [2657]

The Review is also aware of culture, capability, and capacity issues evident within the NDIS Commission. These issues should be addressed to support the NDIS Commission's important and expanded role, as the new National Disability Supports Quality and Safeguards Commission, in promoting quality standards and ensuring the safety of people with disability.

> *"The Commission reviews incident reports but, due to their internal capacity constraints, often does not respond or seek further information until up to twelve months later when key personnel and/or participants have left the organisation... The tone of requests for information can be both negative and disrespectful. Sometimes, the response proposed by Commission staff is out of step with current expectations, such as consideration of person-centred practice or privacy considerations. This gives rise to questions about the current knowledge level of Commission staff involved with incident reviews. The result is that incident reporting can be seen as a compliance requirement focussed on process rather than outcomes." – Provider* [2658]

A disability legal and advocacy service advised that following a complaint, they continued to follow up on behalf of the complainant over an 18-month period. They wrote:

"The Commission finally conceded that they had not communicated with us or our the (sic) client about the final outcome of the investigation until now, had closed the matter without speaking to him, and had communicated only with the Provider." - Villamanta Disability Rights Legal Service[2659]

In addition to general cultural and capability improvements in the NDIS Commission, we have also identified specific opportunities to improve practice, particularly in relation to methods for complaints handling approaches for people with disability, data usage, responsiveness, and relationships and referrals to other regulators (see Action 19.3).

We have also noted the recent Ministerial Direction to the NDIS Quality and Safeguards Commissioner under section 181K of the NDIS Act–No. 1/2023 in relation to taking timely compliance and enforcement action against poor provider performance and reporting quarterly on actions taken.[2660]

We welcome recent work undertaken by both the NDIA and the NDIS Commission to improve culture and capability. Given the importance of culture and capability to the experience of people with disability accessing agencies, ongoing work will be required to effectively deliver our reforms.

4.2.1. The Australian Public Service Commission Capability Review Program

The Australian Public Service Commission (APSC) has established a Capability Review program to continue the Australian Public Service Reform Agenda. Reviews are independent processes and drive discussions around an agency's desired future state, strengths, organisational capability gaps, and what practical actions can be taken for improvement. A report detailing findings of a Review is provided to the Australian Public Service Commissioner, with a view to agencies responding with action plans. Capability review reports and action plans are published on the APSC website.

Reviewers comprise a Senior Review Team including independent reviewers with expertise in public sector operating environments and capability development and senior public servants. The current program of reviews for 2023 includes the APSC, the Department of Health and Aged Care, the Department of Infrastructure, Transport, Regional Development, Communications and the Arts, and the Department of Agriculture, Fisheries, and Forestry.

Given the capability issues we have heard about and those raised through the JSC review, and the scale of reform proposed by our reforms, we recommend that capacity, capability and culture to deliver on this reform agenda be considered by the APSC in future reviews.

When establishing the panels to undertake these Capability Reviews the APSC should ensure that people with lived experience of disability are included.

4.2.2. Action and Implementation Details

Action 22.1: When undertaking capability reviews, the Australian Public Service Commission should have regard to the capacity, capability and culture of the National Disability Insurance Agency, National Disability Supports Quality and Safeguards Commission, and Department of Social Services to deliver relevant reforms.

Capability reviews should include people with disability and assess how agencies can ensure the right skills and capabilities are in place to deliver complex reforms for people with disability and families (including designing and testing reforms with people with disability), manage significant shifts to a broader disability support system and adapt to changes in roles and responsibilities.

Implementation detail:

- The Australian Public Service Commission should develop their review processes for the NDIA, the new National Disability Supports Quality and Safeguards Commission, and the Department of Social Services with people with lived experience of disability. People with lived experience of disability should be included in the review process, including as reviewers.

4.3. Organisational leadership must support ongoing culture and capability uplift

To provide further assurance, the NDIA Board and the National Disability Supports Quality and Safeguards Commissioner should take an active leadership role in ensuring that their organisations have mechanisms in place to develop and maintain the culture and capability to undertake their roles in the disability support ecosystem.

This will require an ongoing commitment to disability aware and person-centred practice, demonstrated by agency-initiated performance and cultural audits. This practice will provide important leadership to the broader disability support sector as well as mainstream services and help to promote a wider uplift in capability across the community in relation to disability aware, socially inclusive, person-centred culture (see Action 22.4).

4.3.1. Action and Implementation Details

22.2 The National Disability Insurance Agency and the new National Disability Supports Quality and Safeguards Commission should publish biennial culture and capability plans every two years, supported by independent audits and staff, participant and stakeholder surveys

Plans should set out specific actions for enhancing, maintaining and continually improving a person-centred and disability-focused culture and high levels of internal capability. These plans should be agreed by the Minister(s) for Disability/ NDIS and published to ensure

transparency and accountability. This should be supported by annual independent performance and culture audits.

Implementation detail:

Biennial plans should set out specific actions for enhancing, maintaining and continually improving a person-centred and disability-focused culture and high levels of internal capability. These plans should be agreed by the Minister(s) for Disability/ NDIS and published to ensure transparency and accountability. This should be supported by independent performance and culture audits every two years.

- By December 2024, commence delivery of a public biennial plan that outlines actions planned to maintain a person centred, disability focused, person centred culture and a high level of capability. The plan should be agreed by the Minister(s) for Disability/ NDIS.
- The new National Disability Supports Quality and Safeguards Commission and the NDIA should establish arrangements for the facilitation of annual independent performance and cultural audits.

4.4. People with disability need a Participant Service Guarantee that includes additional metrics to better measure their experience

The NDIA released a Participant Service Charter in 2020 with five key principles for engaging with NDIS participants: transparent, responsive, respectful, empowering and connected. The Charter sets out the timeframes by which participants can expect responses from the NDIA and Partners in the Community. In response to the Tune Review, the former Government amended the *NDIS Act* to introduce a new, legislated Participant Service Guarantee (PSG) in 2021, following a period of public consultation managed by DSS.

The Tune Review recommended a new PSG should be designed and implemented to 'enhance and strengthen the participant-centred focus of the NDIS'.[2661] The Tune Review also recommended a role for the Commonwealth Ombudsman (Ombudsman) in considering the NDIA's performance against the PSG.

In June 2022, the Ombudsman undertook the first investigation into the preparation of the NDIA to meet the PSG for the 2020-21 financial year. In that review, the Ombudsman reflected on the Tune Review's perspective of the importance of qualitative measures against the PSG and acknowledged existing reporting methodologies. At that time, the Ombudsman recommended that the NDIA develop a PSG performance assessment and reporting framework. The framework should include, at a minimum, the sources of performance information, how each are used in reporting, and details of how often each will be reviewed.[2662]

In 2022, the *NDIS Amendment (Participant Service Guarantee and Other Measures) Act 2022* came into force, which was then consolidated in the *NDIS Act*. The PSG is included in the Participant Service Charter and provides metrics for timeframes in which access, planning, implementation, plan reassessment and variations, reviewable decisions, and nominee matters will be determined. There are also timeframe metrics for the NDIA to respond to complaints and for the call centre to respond to incoming phone calls. The PSG currently requires the NDIA to make decisions about a person's access to the scheme and their plans within certain timeframes, and to meet specific service standards when working with people with disability and their families and carers.

PSG metrics include NDIA timeframes to support people getting started with the NDIS, getting an NDIS plan, and to support participants changing a plan, and making a complaint.[2663] The PSG does not go to the quality or appropriateness of support provided by the NDIA, or to improving the transparency of decision-making processes.

As noted in Chapter 2, the period following the introduction of the PSG coincided with a period of increased NDIS Act section 100 reviews and AAT appeals. It is possible that the introduction of the PSG without any increases in staff resources contributed to this negative experience for participants.

We have heard a focus on timeliness only may come at the expense of good outcomes. For example, in commenting on the achievement of long-term outcomes, Mission Australia told us:

> *"The Agency prioritises key performance indicators (KPIs) that measure the performance of transactions and the timeliness of completing specific tasks within dedicated timeframes. This is important, but it means that the quality of service delivery is not highlighted like it should be under the Participant Service Guarantee or as is already captured in the Participant Experience Delivery KPIs. This reinforces the view that the NDIS role is measured by transactions rather than identifiable outcomes for people with disability." - Mission Australia* [2664]

Further, some participants advised us that the timeframes in the PSG actually worsened, rather than improved, their customer service delivery experience.

> *"That complaint, like my first, was closed prematurely, to meet the Participant Service Guarantee deadline, without acknowledging this information or my other requested outcomes and concerns. They are misrepresenting these statistics and KPIs." - Participant* [2665]

Establishing timeframes and performance metrics was a welcome development in the ongoing implementation of the NDIS, but it cannot be at the expense of the quality of decisions. It is clear there are further opportunities to strengthen the PSG to improve participant experience and the quality of decisions made. For example, participants should have opportunities to provide satisfaction scores on NDIA interactions including access requests and internal reviews.

Action 22.3: The Australian Government should re-design the Participant Service Guarantee to prioritise high quality, transparent and efficient decisions and improved participant experience.

The Participant Service Guarantee should include new metrics in addition to timeframes to measure quality of decisions and incentivise better participant experience. This could include quality and transparent decisions for participants, participant satisfaction scores and employee satisfaction scores, including for partners. This should be designed with participants.

Implementation detail:

- DSS, working with the NDIA, should re-design the Participant Service Guarantee to include metrics in addition to timeframes to incentivise better participant experience. The new guarantee should include:

  - Participant satisfaction scores

  - Participant effort scores (the degree of difficulty of an interaction)

  - Employee turnover rate (including for partners)

  - Employee satisfaction scores (including for partners)

- At a minimum, these scores should relate to the following interactions:

  - Access requests

  - Budget reviews

  - Interactions with Needs Assessors

  - Queries and complaints raised with the National Call Centre

  - Interactions with Navigators

  - Internal reviews

  - The NDIA should design test and implement tools and systems, including through the NDIS Experience Design Office where appropriate, to enable Participants and their nominees to immediately self-report satisfaction and the effort required to complete an interaction with the NDIA.

  - Employees to understand why a particular score has been given by a participant or nominee.

  - Ensure all major operational changes go through an independent impact analysis, testing and evaluation process prior to implementation in line with the Commonwealth Evaluation Policy and best practice guidance from the Office of Impact Analysis.

- Invest in their service design, data, and digital and evaluation capabilities.

- Work with Disability Representative Organisations and training experts to design and test compulsory trauma and disability training for all frontline staff.

- Establish a multidisciplinary implementation team including representatives from the sector, people with disability and experts in technical assessment to lead the design of metrics.

- Improve the approach to information design and provision to ensure all people with disability can access the information they need when they need it and reduce barriers to understanding and accessing the NDIS

- Ensure all information products are designed and implemented to meet the accessibility requirements of the Australian Government Digital Service Standard.

- Report to Australian Disability Ministers annually on compliance of all of its products and services with the Australian Government Digital Service Standard Criteria.

- Better design information products about the NDIS with the intended audience, including:

  o Tailoring products to meet the needs of people with intellectual disability, and people with disability who experiences of intersectionality.
  o Delivering information via a broad range of accessible channels.
  o Ensuring information is provided in a strengths-based and trauma-informed manner.

- Re-design their information management systems to enable participants and their nominees to view, upload and have continued access to the information they provide the NDIA, as well as all assessments, plans and decisions that affect them.

- This should be linked seamlessly to the NDIS online marketplace to enable a single NDIS interface for participants and nominees.

4.5. All governments must model and promote disability aware culture and capability

Currently, there is no standard requirement for public servants in government agencies delivering disability policy to demonstrate skills and capability in disability awareness, social models of disability, or human rights.

It is not enough to have only high level person-centred, disability aware capability in government agencies that are public facing. It is also essential that people employed within government disability policy, operational, or regulatory areas demonstrate the same level of capability.

As part of the new Disability IGA, all parties should commit to developing and reporting against measurable disability culture and capability outcomes across all government disability functions. This should include a report by each agency of the number of people with disability and those with other lived experiences of disability who are employed.

There are many Australian Government, state and territory public servants and contractors engaged in the development and implementation of disability policy, programs, regulation and delivery. We acknowledge actions taken by governments to increase the numbers of people with disability employed (for example, the NDIA's Annual Report for 2022-23 states 19 per cent of staff have a disability).[2666] This is very welcome and should be applauded, but increases should continue.

The NDIA is a public sector outlier when it comes to employing people with disability. In May 2019, the Australian Government committed to the target of a 7 per cent employment rate for people with disability by 2025.[2667] Yet over the last two decades rates of employment of people with disability reported in Australian Government public service human resource systems have remained steady at around four per cent.[2668] It should be noted that in the same year, 9.1 per cent of respondents to the 2021 APS Employee Census identified as having a disability.[2669] This in itself indicates there is more work to do.

Some state and territory governments also have disability employment targets or are working towards establishing them. The leader is Victoria, which has set a target of 12 per cent of Victorian Public Servants having a disability by 2025.[2670] In 2022, 7.3 per cent of the 24,542 Victorian public servants who completed the People Matter survey in 2022 identified as having a disability.[2671]

We believe in addition to increasing employment of people with disability and lived experience of disability, all public servants and contractors should understand the social model of disability, commitments made by governments through the UNCRPD, and demonstrate an understanding of disability awareness, and intersectionality. As 1 in 5 Australians have a disability, this is a core area of understanding for all public servants. There should be a minimum core basic knowledge and skills requirement for all public servants and contractors undertaking disability activities. This would hold public servants to the same standards as providers of disability supports operating within the disability support ecosystem.

We also believe that governments should consider whether additional clauses should be included in commissioning and funding agreements to embed culture and capability outcomes including in relation to the employment of people with disability.

4.5.1. Action and Implementation Details

Action 22.4: The Disability Reform Ministerial Council should agree measurable culture and capability outcomes as part of new funding arrangements

All Australian, state and territory government agencies responsible for disability policy and/or service delivery should model best practice in the promotion of disability aware, socially inclusive, person-centred culture. These outcomes should be embedded in funding arrangements (see Action 20.2), documented in the Disability Support Outcomes Framework (see Action 23.1) and reported to the Disability Outcomes Council (see Action 20.5)

> *Implementation detail:*
>
> - Australian government and state and territory governments should agree to the inclusion of measurable disability culture and capability outcomes across policy and service delivery in the new Disability IGA. (Recommendation 20).
> - Led by the Australian Government, all governments should develop performance measures to be included in the Disability Support Outcomes Framework (Action 23.1) to be monitored, reviewed, and reported on by the DOC (Action 20.5).
> - Noting existing requirements for NDIS providers under NDIS Practice Standards, governments should consider whether additional clauses should be included in commissioning or funding agreements to embed culture and capability outcomes including in relation to the employment of people with disability.

5. Measure what matters, build an evidence base of what works and create a learning system

5.1. The unified disability support ecosystem needs to have better ways of measuring, collecting and using evidence

We have found the NDIS has not been set up in a way that enables continuous learning. There is limited data or evidence to enable accountability and transparency.

Successful reforms need to be supported by a system that prioritises achieving outcomes and continuous improvement. The NDIS supports over 610,000 participants with disability through a $35.1 billion investment in 2022-23.[2672] This magnitude of investment should be backed up by a rigorous commitment to evidence-based practice, evaluation and continuous improvement

There are significant gaps in the evidence base and data that makes measuring what matters for people with disability difficult.

Given the importance of disability support and its intersection with other systems of support such as health, education, housing and foundational supports, greater investment by all governments is required in better research, evaluation and knowledge translation.

Future investments in data infrastructure should cover both foundational supports and the NDIS. This is critical to provide an evidence base that underpins an effective disability support ecosystem for all people with a disability.

There should be a commitment to greater sharing of disability data in a safe and secure manner with researchers, service providers and governments to support improved evaluation. These investments can build the foundations for a culture of continual learning and innovation for the whole disability ecosystem.

A more complete evidence-based picture of the disability landscape will help the scheme demonstrate value for money for governments and taxpayers. It will also help participants improve outcomes and meet their goals more effectively through innovative and evidence-based supports.

There is an opportunity to build on the NDIS and the NDDA to become a world leader in disability research, policy and practice.

Recommendation 23: Measure what matters, build an evidence base of what works, and create a learning system

📑 Legislative change required

- Action 23.1: National Cabinet should agree to replace the current NDIS Outcomes Framework with a new Disability Support Outcomes Framework.
- 📑 Action 23.2: The Department of Social Services, in consultation with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and the Independent Health and Aged Care Pricing Authority, should establish and manage a NDIS Evidence Committee to provide guidance on reasonable and necessary disability supports.
- 📑 Action 23.3: The Department of Social Services should establish a new Disability Research and Evaluation Fund to coordinate and fund research and independent evaluation activities.
- Action 23.4: All Australian governments should agree to jointly invest in actions to improve disability data quality and sharing.
- Action 23.5: The Australian Government should ensure that all disability reporting mechanisms facilitate the collection, analysis and publication of intersectional indicators.

5.2. The current NDIS Outcomes Framework is not fit for purpose

5.2.1. The current outcomes framework could be improved

The NDIA manages a NDIS participant outcomes framework which relies heavily on participant satisfaction surveys and there is limited data on participant outcomes and scheme effectiveness.[2673]

The NDIA releases data through quarterly performance reports, aggregated datasets and reports, based on its own analysis. While the current NDIS outcomes framework is useful, the coverage is limited and does not include whole of system interactions (including between the NDIS, mainstream and other related service systems and programs). Reported outcomes are not directly linked to scheme costs and quality of life and wellbeing for participants and their families.

We note the NDIA is in the process of developing new methods to link expenditure and support types to outcomes through the Investment Effectiveness Program. This should provide a better understanding of the links between NDIS goal setting, services, costs and benefits.[2674] The NDIA also has partnered with the Monash University Centre for Health Economics to create a new index

that measures the wellbeing of people with disabilities aged 15 and above, including NDIS participants.[2675]

The Review commissioned Taylor Fry to conduct further analysis on developing an outcomes framework for the disability supports system, which takes into consideration the current NDIS Outcomes Framework.[2676] Taylor Fry's Report identified a number of limitations in the current outcomes framework, including:

- There are relatively few objective measures in the current Framework. While some questions are objective (for example, employment status), many are more subjective (for example, does your child manage their emotions well?). This can be a challenge if expectations change or there are short-term changes in views. Incorporating other administrative indicators may complement current measures.
- There is limited ability to measure comparable outcomes outside the scheme. By design, the scope of questions are limited to NDIS participants and their carers. Unless a question matches other surveys (for example, employment), the 'gap' is less apparent. Alignment to the Survey of Disability, Ageing and Carers (SDAC) or other surveys will improve comparability.
- It is challenging to measure progress. Currently, outcomes are often tracked for people by duration in the scheme, using first response as a baseline. However, since outcomes will change with age and other time-varying features (for example, disability severity), appropriate controls are needed.
- There is a limited focus on goals of participants and whether progress is being made to achieving these goals. The linkage between the participant's goals, their outcomes and the spending, particularly for capacity building, is not drawn out.
- The indicator set is relatively large, meaning that presenting a comprehensive view is difficult.

5.2.2. A new Disability Support Outcomes Framework should cover the whole disability support ecosystem

We consider a new Disability Support Outcomes Framework should be developed to replace the NDIS Outcomes Framework. Covering both foundational and NDIS supports, the new Framework should:

- Be led by DSS and include the voices of people with disability (including NDIS participants), carers and service providers.
- Include consideration of both quantitative and qualitative measures.
- Describe measurable targets and standards at the individual, provider and system level that are relevant and fit-for-purpose

    - At the provider level, it should use established standards and reporting, drawing on the approach proposed for provider performance measurement (see Action 12.3).

    - At the individual level, this should also include wellbeing measures.

- Include clear roles, responsibilities and accountability for disability support outcomes, with effective and independent oversight to monitor, review and report against outcomes in the new Framework (see Action 20.5).

  - This should also be linked to the new Disability Research and Evaluation Fund, which once established, through commissioned research can identify measurement gaps across the disability support ecosystem, including in the new Framework (see Action 23.4).

- Be linked to new funding arrangements (see Action 20.2) to further clarify roles and responsibilities, rebalance risk sharing, and develop measures to prioritise and uphold reporting on the Framework. This includes:

  - New practical clauses to promote inclusion of people with disability and increased accessibility in mainstream services.

  - Documenting agreed, modelled, and best practice outcomes in the promotion of disability aware, socially inclusive, person-centred culture, also outlined in new funding arrangements (see Action 22.4).

5.2.3. Action and Implementation Details

Action 23.1: National Cabinet should agree to replace the current NDIS Outcomes Framework with a new Disability Support Outcomes Framework.

The new Framework should be focused on objectives and key results covering both foundational and NDIS supports. Accountability for disability support outcomes should include measurement against agreed objectives and key results to drive an agenda of continuous improvement. Development of the Framework should be designed with people with disability and led by DSS (see Action 20.5). The Framework should be included as a schedule in the new Disability Intergovernmental Agreement (see Action 20.1).

Implementation detail:

- DSS should lead the development of a set of objectives and key results that identify disability support outcomes over a specified time period.

  - The framework should describe measurable targets and standards at the individual, provider and system levels. Targets must be relevant and fit-for-purpose. Targets and standards at the provider level should draw on established standards and reporting, as well as the approach proposed for provider performance measurement (see Action 12.3).

  - The process for developing the new framework should be designed with people with a disability (including NDIS participants), carers and service providers to ensure outcomes for people that are valued by them, and include consideration of both quantitative and qualitative measures.

5.3. Supports and management especially early intervention need to be underpinned by a stronger evidence-base to guarantee net benefits and sustainability

The NDIS currently provides significant funding for some therapies, interventions, services and assistive technologies that have not been proven to help people with disability and in some cases cause harm.

Significant evidence gaps persist in areas of critical policy to the NDIS, particularly with respect to early interventions for children. There is relatively little high-quality evidence about what interventions have the potential to improve outcomes in a cost-effective manner, and potential harms associated with interventions. For instance in the Autism CRC's umbrella review of autism interventions only 4 of 58 systemic reviews examined met all criteria consistent with high methodological standards, and only eight included any information about potential harms or negative consequences related to the interventions delivered.[2677]

In the Autism CRC's umbrella review of autism interventions *no* studies identified results with respect to child satisfaction or wellbeing.[2678] When combined with overall low methodological quality, and a lack of evidence concerning safety, this raises concerns governments may be inadvertently subsidising a range of harmful interventions for vulnerable children.

There is also a lack of knowledge concerning assessing functional capacity and support needs for particular disability cohorts, most notably for neurodivergent people.

For example, there is an ongoing conflict between what is described as best practice in historical versions of guidelines and other research and what government is willing to fund. In particular, previous research and guidelines for autistic children has suggested particular intensities of therapy and levels of Applied Behaviour Analysis (ABA)-based therapies are best practice for some children (or similar models). This evidence has been used successfully at AAT to overturn decisions by the NDIA that had been based on the contemporary best practice guidelines.

There is also the question of whether the intervention is demonstrably safe to the child and avoids the risk of harm. This is a particular question for ABA-based therapies and interventions and whether they are fully consistent with the social model of disability underpinning the NDIS, and respect for the rights of people with disability and children more broadly. We heard from autistic people and families about their experiences and perspectives of ABA-based therapies.

> *"There is increasing evidence clinical settings and "evidence-based practices" such as therapies that use applied behavioural analysis and ABA-like methods and theories (especially for autistic children) are causing long-term harm for short-term "normality". The focus of many of these practices is not support, it is to make a child look like other children, evidence is showing this causes long-term harm including lifelong PTSD." – Participant[2679]*

The NDIS is not based on the medical model of disability, and is designed to provide a broad range of supports to increase participant engagement in community and economic activities. However, where therapies, interventions, services or assistive technologies claim to provide therapeutic benefits, their suitability for NDIS funding should be rigorously assessed. Similarly, capacity building supports funded by the NDIS need to demonstrate evidence of improving capacity, avoidance of harms, and cost-effectiveness. In measuring both benefits and costs the views of people with disability must be included.

5.3.1. Other similar policy areas have stronger institutional controls concerning evidence-based practice

Other areas provide more stringent controls on what therapies, interventions or supports can receive government funding based on comprehensive assessment of effectiveness. For instance, the Pharmaceutical Benefits Advisory Committee (PBAC) is an independent expert advisory body appointed by the Australian Government with membership drawn from health professionals, health economists and consumer representatives. Its primary role is to recommend new medicines for listing on the Pharmaceutical Benefits Scheme (PBS). No new medicine can be listed unless the PBAC makes a positive recommendation. The PBAC has two sub-committees: one focused on scientific and clinical aspects of medicine approval and the other on the economic dimensions of the decision to list a medication and provide a government subsidy.

Similarly, the MBS is a list of health services, including consultations, diagnostic tests and operations for which Medicare rebates, essentially government subsidies, are available. The MBS is maintained by the Department of Health and Aged Care, and implicitly involves the Australian Government making a cost-benefit decision in relation to which medical procedures and therapies it is willing to subsidise. Each item in the MBS must first pass through the Medical Services Advisory Committee (MSAC), which provides advice after reviewing the evidence base of a service to make sure it works and it can provide value for money. In this way, the MBS supports Medicare to be provided as an effective and sustainable uncapped, demand-driven program.

"Clarity on these issues, including value for money, is important in the context of the NDIS given that one of the criteria on which the NDIA makes decisions in relation to reasonable and necessary supports is whether or not it is value for money. We have heard this is an area of deep frustration for participants and their families: "Many of the NDIA delegates who make decisions about access, eligibility, and 'reasonable and necessary' supports do not have any understanding of disability, the lived experience of disability (lived experience of disability = having a disability or mental illness) or even basic medical condition terminology. They certainly don't understand the reports provided by specialists, which they ask for, won't admit it and refuse to fund because they don't understand what they are reading. Therefore, this lack of understanding means that they cannot properly evaluate the criteria around 'value for money', which is framed as the total amount of money already spent on you, rather than the value for money provided by the requested support, in terms of how it assists the NDIS participant to meet their plan goals." – Participant [2680]

5.3.2. An NDIS Evidence Committee is needed to evaluate and recommend evidence-based policy and disability supports.

The NDIS currently lacks an independent and transparent oversight mechanism to determine the appropriateness and effectiveness of supports funded through the NDIS. While the level of evidence required for government subsidisation through the NDIS should not be lower than other areas, there are significant challenges when measuring social and economic benefits and the many factors that affect the lives of people disability.

Choice and control is a foundational principle of the NDIS, but this has always been balanced by funded supports being reasonable and necessary. Choice and control does not mean that the NDIS should fund interventions that are, for example, potentially harmful to children or participants that otherwise may have a limited capacity to provide informed consent. It also does not mean that the NDIS should fund services or technologies that are claimed to have therapeutic benefits without a rigorous assessment of evidence of benefits, potential harms, as well as cost effectiveness.

A NDIS Evidence Committee should be established to develop rules and guidance on the types of supports that are eligible and ineligible for NDIS funding, as well as to advise the NDIA and other agencies on evidence-based approaches to NDIS policy and operations. Funding from individual budgets should not be used for ineligible supports nor should exceptional circumstances be sought for funding of these supports.

5.3.3. Action and Implementation Details

Action 23.2: The Department of Social Services, in consultation with the National Disability Insurance Agency, the new National Disability Supports Quality and Safeguards Commission and the Independent Health and Aged Care Pricing Authority, should establish and manage an NDIS Evidence Committee to provide guidance on reasonable and necessary disability supports.

The Evidence Committee should evaluate and recommend evidence-based therapies that warrant NDIS support in the budget setting process or funding as foundational supports with regard to benefits, quality, safety, and cost -effectiveness. The Evidence Committee should also advise agencies and governments on other evidence related dimensions of NDIS operations. The Evidence Committee should address gaps in scientific and economic insight by assessing and determining the efficacy and cost-benefit of supports for NDIS funding. Practice Standards for providers would ensure they deliver supports that are safe and evidence-informed, supported by regulatory oversight by the new National Disability Supports Quality and Safeguards Commission. The Evidence Committee's annual work plan will be approved by Disability Reform Ministerial Council. While Evidence Committee deliberations on the merits of supports will be independent and transparent, any recommendations concerning the eligibility of supports for NDIS funding will require final approval by relevant decision-makers.

Implementation detail:

- DSS to establish the NDIS Evidence Committee. The Evidence Committee should be modelled on the PBAC and MSAC and operate as an independent body.
- Once established, the Evidence Committee should in the first instance prioritise deliberations on early interventions for children and behavioural interventions.

5.4. High quality, independent research is required to ensure there is a strong evidence base underpinning disability funding and investment

There is an overall lack of high-quality evidence underpinning many disability supports, interventions and assistive technologies funded by the NDIS. There is also a lack of evidence about what works best for people with a disability in a range of foundational support settings. Disability research is significantly underfunded relative to other research domains of similar policy relevance and importance to citizens and governments.

We have heard research and evaluation activity is insufficiently independent from stakeholders, service providers or governments. There are also concerns NDIA research and evaluation activity lacks independence and transparency. We need a fundamental change in research funding and output to address persistent and new evidence gaps. There is also a pressing need for building policy relevant research capacity and improved knowledge translation to address knowledge – implementation gaps.

5.4.1. There are considerable knowledge gaps in disability research

Between 2018 and 2020 only 2.3 per cent of Australian-related disability research published in journals related to the NDIS.[2681] Policy-critical research related to housing (1.7 per cent), economic costs (0.8 per cent) and behaviour support practices (0.5 per cent) also received very little research attention.[2682]

The National Health and Medical Research Council (NHMRC) is considered a viable funding source for disability research, however funding is specific to medical and health research. Supported research does not necessarily integrate a full range of social science-based disciplines that can be relevant to evaluating disability services and supports comprehensively, including from the perspective of the social model of disability.

Despite the prominence of the NDIS in the national policy discourse over the past decade, disability research has attracted minimal philanthropic and Australian Research Council (ARC) research funding.[2683] High quality disability research must engage people with disability in the research process. However, too little research that is currently funded in the Australian context is truly participatory in nature. A lack of guidelines for the ethical conduct of research with people with disability and inclusive research guidelines covering participatory research principles contribute to the under-representation of the voices of people with disability in disability research.[2684] The lack of a voice for children in disability research increases risks that related disability supports and interventions may not improve welfare or respect the human rights of children.[2685]

The establishment of the National Disability Research Partnership (NDRP) should assist with building capacity for research including among people with disability and community organisations. NDRP is also developing advice for ethics committees on how best to include people with disability in research so it is undertaken with them in a participatory way.

5.4.2. Knowledge gaps persist in part because disability research is underfunded relative to its policy importance

Increased efforts to boost disability research are underway. For instance, the Australian Government has provided funding of $12.5 million over 2022-23 to 2024-25 to establish the NDRP.[2686] The NDRP will facilitate a participatory and collaborative disability research program to build evidence to inform disability policy and practice and build capacity.

In addition, governments, the NDIA, the Australian Research Council and the National Health and Medical Research Council (NHMRC) fund a significant national disability research program across a range of research institutions, disability Cooperative Research Centres (CRCs) and centres of excellence.

However, existing bodies do not fund or undertake research at the scale necessary to address policy-critical evidence gaps. In particular, disability research outside of the medical context is significantly underfunded relative to its importance to the wellbeing of people with disability, their families, carers, and government policy settings.

Governments and the disability community would benefit from a significant additional source of research funding to address priority areas of research across the Australian disability support ecosystem. Given the world-leading nature of the NDIS – there is nothing like it anywhere in the world and there is great international interest in the NDIS – there is an opportunity for Australia to become a world leader in disability research.

By way of example, the Australian Governments $20 billion Medical Research Future Fund (MRFF) is expected to fund $870 million in research activities in 2023-24.[2687] The Report on Government Services 2023 identified $132.2 billion in recurrent health expenditure undertaken by combined Australian governments based on the latest available data.[2688] By comparison, Australian governments spent a combined $35.1 billion on the NDIS in the year to 30 June 2023.

If research funding were to be provide based on relative fiscal importance, the new DREF would have a funding endowment of around $5.3 billion at its disposal, and fund around $230 million in annual research output.

In this context the proposed annual Australian Government funding commitment towards the DREF is relatively modest, although it is a vital and necessary step in starting to provide the evidence base required to support a more evidence-centred NDIS.

5.4.3. Research methods and outputs need to be trusted by people with disability

We heard concerns that NDIA-commissioned research lacks independence and transparency and that its quality and quantity is insufficient to address evidentiary requirements underpinning NDIS operations.

Many research and evaluation activities are often viewed as insufficiently independent from governments, interest groups, service providers and clinicians. Misaligned incentives can contribute to poor research quality, and a lack of more arms-length evaluation activity being undertaken and published. [2689]

5.4.4. A new independent research fund is required to address knowledge gaps and support evidence-based practices

To address the above concerns, governments should establish a Disability Research and Evaluation Fund (DREF) that would commission and fund research necessary to improve outcomes for people with disability, their families and carers. This should benefit all people with disability, including both NDIS participants and those receiving foundational supports.

In order to seed the DREF, Australian Governments should consider using the Reserve Fund. We note that the future of the Reserve Fund is a matter for Treasurers. However, using the income from the Reserve Fund to fund research would be consistent with its purpose of benefitting people with disability and would provide a very strong message that Australian Governments are committed to research and evidence-based disability policies.

It will be able to complement the work of existing CRCs, and Centres of Research Excellence. The DREF will provide an additional source of partner funding to support the research activities of these bodies. Being independent from the NDIA, and with entirely transparent research projects and outputs, the DREF should address concerns about organisational capture of the research agenda and outputs.

Building research capacity and so funding programs of work not just projects must be another core aim of DREF. This should include supporting more researchers with disability and lived experience of disability.

The DREF should also invest in improving research quality and supporting participatory research. The DREF could lead the development for the ethical conduct of research with people with disability, and the development of research guidelines concerning participatory research principles.

The DREF should also encourage linkages with the best international researchers to assist with addressing pressing policy and evidentiary challenges. Through strengthening domestic research capacity and international linkages the DREF will aim to position Australia as a world leader in disability research over the longer term.

The DREF should also facilitate disability researchers engaging with the Australian Bureau of Statistics (ABS) and Australian Institute of Health and Welfare (AIHW) concerning improving data availability and quality. This should include improvements in the National Disability Data Asset, which will bring together de-identified information from different government agencies about Australians with disability and without disability, the ABS Survey of Disability Ageing and Carers and linkages via the Person Level Integrated Data Asset (PLIDA), which is an Australian Government administrative data repository containing linked socioeconomic and population demographics datasets (including the Census) over time.

Overall, we believe there are very significant opportunities for a DREF to complement and strengthen the disability research ecosystem in Australia, in ways that are focused on improving outcomes for people with a disability and their families in Australia.

5.4.5. Action and Implementation Details

Action 23.3: The Department of Social Services should establish a new Disability Research and Evaluation Fund to coordinate and fund research and independent evaluation activities

The Disability Research and Evaluation Fund (DREF) should be in the order of $40-50 million per year and consideration could be given to drawing on income from accumulated unspent funding from jurisdictions' contributions to NDIS transition (the proposed 'Reserve Fund'). The DREF should fund the development of a robust evidence base to inform the operations of the disability support ecosystem. This should include identifying and addressing knowledge gaps in Australian and international disability research relevant to the Australian context, and supporting the work of the NDIS Evidence Committee (see Action 23.2). The DREF should also fund greater data investment and research on the experiences of people with disability not eligible for NDIS to facilitate collaboration in the disability sector and improve the evidence underpinning effective support for people outside the scheme. The DREF should support and promote knowledge translation of best practice evidence by policy

makers and service providers. It should support leading research initiatives and seek to build disability research capacity, so that Australia can become a world leader.

Implementation detail:

- DSS to develop a disability research, evaluation and capacity building strategy to identify DREF's initial research, capacity building and knowledge translation priorities for endorsement by DRMC, including consideration of future annual research and evaluation priorities in consultation with the NDIS Evidence Committee, NDIA, DSS and the new National Disability Supports Quality and Safeguards Commission (in particular the Deputy Commissioner for Quality and new quality function, See Action 12.1).
- The Australian Government to commit to establishing an appropriate governance framework, and aim to fund an ongoing annual research program of around $50 million via the DREF once established. This amount should be indexed for inflation.
- This framework could include setting out the responsibilities of the DREF's such as:

  - applying a 'whole-of-system' focus on policy-relevant research relevant that extends beyond the current remit of the NDIA's Research and Evaluation Function

  - ensuring DREF-commissioned research and evaluation activities being fully independent of governments, the NDIA and the new National Disability Supports Quality and Safeguards Commission, and transparent to the general public

  - establishing a disability research hub that synthesises and disseminates high quality research in accessible formats

  - engaging with the ABS and AIHW concerning improving data availability and linkages via PLIDA, SDAC and the NDDA (Action 23.4)

  - engaging with the ABS, AIHW and NDIA to ensure that World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) disability concepts and classifications are used to underpin relevant NDIA and NDDA data structures. (Action 23.4)

  - a commitment to research excellence.

- The Australian Government should consider incorporating existing research and evidence related strategies concerning the NDRP and NDDA within the remit of the DREF.

5.5. Higher quality and more frequently published disability data is required to improve the Scheme

There is a need for high quality longitudinal NDIS administrative data to monitor and evaluate scheme performance and inform policy. Linked administrative data is critical for improving our understanding of life trajectories of people with a disability both inside and outside of the scheme.

It also enables policy makers and researchers to better evaluate the effectiveness of disability supports and track participant outcomes over time.

There has been significant progress made in the availability and use of NDIS data but more is required to support comprehensive outcomes analysis and research and evaluation. NDIS data has been linked with PLIDA, NDDA and for reporting on outcomes under the ADS.

5.5.1. The lack of high-quality disability data limits the capacity to evaluate and govern the scheme

Data is currently presented in a form that makes it difficult to relate to other linked administrative datasets, and to be used for multiple purposes. Processes and systems for accessing and using this data are often duplicative, time-consuming and administratively inefficient. A more effective approach to governing data access, based on the 'Five Safes' framework, would significantly expand research and evaluation output and quality. [2690]

NDIS administrative data is not structured in a manner that is consistent with the International Classification of Functioning, Disability and Health (ICF) domains. The ICF is used by the World Health Organisation and is the international standard to describe and measure health and disability. Failure to use ICF domains undermines the value of NDIA data for research due to a lack of conceptual clarity in disability classification, and an inability to readily compare to other data assets that have an ICF-aligned data structure.

There is a lack of data concerning people with disability outside of the scheme, including those ineligible for the NDIS. The need for data about the outcomes and experiences of people with disability in foundational support systems will become more pressing under our proposed reforms as foundational supports will play a larger role in the disability supports ecosystem.

Recent changes in disability prevalence rates, and increased funding for therapy supports requires linked comprehensive datasets that are updated regularly. The ABS's SDAC, which is linked to the Census, remains a rich source of policy relevant survey data and important reference point concerning the lives of people with disability outside the NDIS and their family members. A three yearly cycle for SDAC should be maintained.

In their 2011 Inquiry Report, the Productivity Commission identified improved labour market outcomes for NDIS participants and their family members as a key likely source of benefits associated with the provision of enhanced disability supports under the scheme. However, existing outcomes reporting, while helpful, does not facilitate a true assessment of the direct impact of scheme participation on labour market outcomes for participants and family members.

Currently ABS labour force survey data and other available administrative and survey datasets are not well adapted to addressing questions of how labour market outcomes for people with disability and their family members are evolving over time, and how outcomes may have been affected by particular policy interventions, including participation in the NDIS.

5.5.2. Data improvements and better sharing of data in a safe, secure and ethical way will drive innovation and continuous improvement in the NDIS

To address the above issues, more disability-relevant longitudinal administrative data from the NDIS, foundational and other policy areas, as well as enhanced survey data capable of providing longitudinal insights, needs to be made available in a secure and timely manner for researchers to support policy evaluation and contestability.

The NDIA is already building one of the most comprehensive population-based longitudinal databases on disability, in the world. However, the benefits have not been realised as access to data, and linkage to other administrative datasets, has so far been limited.

Greater access to timely data, including on quality and safeguards, will allow researchers to support participants, providers and governments to measure outcomes and improve the effectiveness of the NDIS.

The NDDA is being established by the Australian Bureau of Statistics (ABS) and Australian Institute of Health and Welfare (AIHW) under guidance from the NDDA Advisory Council. It includes strong governance mechanisms to provide for data integrity, Five Safes and data sovereignty.

The proposed NDDA is intended to connect data concerning people with disability and their family members from different government agencies to help better understand their life journeys and experiences. Establishing the NDDA is important for supporting an evidence-based approach that measures the effectiveness of overall disability support systems. The NDDA could also be expanded to include non-government data, such as provider data to measure outcomes over time.

The NDDA should be based on a federated approach to data linkage as it will promote greater use of data and broader data linkage across agencies, service providers, and participants. Under this model, data custodians (including non-government entities) would maintain control and influence over the data they contribute but agree to link and share data upon request based on agreed transparent principles and governance arrangements. A federated approach can help improve coordinated service delivery and care.

Investing in the NDDA should be a priority for Disability Reform Ministers, given that it represents critical data infrastructure through the linking of NDIS, social security, tax, employment, medical, health, hospital, housing and justice data. It also uses Medicare data as its reference point and so can be used to compare outcomes for people with and without disability and allow for different definitions of disability. It is an essential and unique resource on which future research, evidence and practice will be built.

In December 2022, we provided advice to Disability Reform Ministers in support of the establishment of the NDDA. We very much welcome the Australian Government decision in the May 2023 Budget to fully fund the NDDA for the next two years. However, funding beyond this period is not yet secure and we strongly recommend ongoing funding for the NDDA.

The NDDA is critical to improving our understanding of NDIS participant pathways, measuring outcomes and understanding scheme effectiveness. Rare Voices Australia noted the value of the

NDDA as a single source of combined data from different platforms in its submission to the Review and stated they were:

> *"Encouraged by the government's commitment to the National Disability Data Asset (NDDA). This platform will provide a single source of information combining Commonwealth, state, and territory data on people with disabilities, significantly enhancing research, policy development and service delivery. RVA eagerly anticipates participating in the design and implementation of the NDDA to ensure the needs of people with disabilities who also have a rare disease are recognised as an important cohort." - Rare Voices Australia* [2691]

The NDIA, when structuring NDIS data, and ABS and AIHW, when structuring the NDDA, should adopt the International Classification of Functioning, Disability and Health (ICF) domains to allow better comparison of Australian experiences in the international context, and strengthen the relevance of Australian data and Australian research in advancing understanding of disability and disability supports.

There are also opportunities to improve data scope and quality, as set out in the ADS's *Data Improvement Plan*.[2692] Further, by making the NDDA available to researchers, there will be improvements in data quality. This has been the experience, when making other large administrative datasets available to researchers, with appropriate safeguards for privacy, such as with the Australian Taxation Office data.

5.5.3. Action and Implementation Details

Action 23.4: All Australian governments should agree to invest in actions to improve disability data quality and sharing.

This should build on the Disability Reform Ministerial Council (DRMC) agreement for the NDIA to improve the quality, availability and use of disability data through additional investments and fostering a culture of continual learning. The NDIS data structure should be aligned with the ICF. All governments should invest in developing a robust evidence base on the lifetime experiences of people with disability. This should include investing in the NDDA, ABS SDAC, engaging with ABS to improve data availability including in the PLIDA, improved longitudinal insights into labour market barriers, and other disability related data. Governments should also commit to greater collection and sharing of data regarding foundational and mainstream services with linkage to other administrative datasets.

Implementation detail:

As agreed by DRMC in December 2022, the NDIA should develop a comprehensive, public data strategy in consultation with people with disability, to support the effective, safe, ethical and secure use and sharing of NDIA data. At a minimum, the data strategy will outline how NDIA will share improved data in a safe, secure and timely way that supports the interests of

people with disability, and identify opportunities to link with and enhance disability data collected through the NDDA. The NDIA will also commit to linking NDIA data of participants who applied but were not eligible for the NDIS with other Australian Government Administrative datasets to expand the knowledge base of disability participant supports and pathways in a safe, secure and ethical manner.

Department of Social Services with states and territories should:

- Develop an ongoing data collection strategy for new data items to address measurement gaps in the new IGA (Action 20.1); the new Disability Support Outcomes Framework. (Action 23.1); and to support ongoing outcomes monitoring, research and evaluation priorities.
- Support the sharing and linking of longitudinal scheme administrative data in the NDDA for improved measurement of outcomes, and support the safe, secure and ethical use of the NDDA by researchers and, over time, service providers in consultation with people with a disability.
- Promote greater data availability and improve linkages in datasets such as PLIDA and NDDA by collaborating with relevant data bodies including the ABS and AIHW.
- Consider the development of a real-time digital system-to-system data sharing for service delivery purposes and sharing of different levels of data, as legally allowed.

The ABS should commit to improving longitudinal insights into labour market barriers, successful transitions and outcomes for people with disability and their family members, through integrating Census, Labour Force Survey, and administrative data.

In the context of the new Disability IGA, Australian governments should agree to improving data sharing, availability and linkages with respect to the outcomes of people with a disability and their families in foundational and mainstream services under the guidance of people with disability.

5.6. Improving collection and reporting of intersectional data needs to be prioritised across all aspects of the Scheme and the disability ecosystem

All people with disability should be able to engage with informative and accessible data and reporting insights produced by governments. These insights should be informed by inclusive data collection, analysis and reporting against intersectional characteristics.

First Nations people, women and other intersectional cohorts, such as LGBTIQA+SB and culturally and linguistically diverse communities, must be meaningfully counted, included and resourced to build data infrastructure, practices and processes that give voice to their experiences.

The lack of information on these groups is, in part, caused by the known limitations of NDIS, SDAC and other existing disability data collections.

The Australian Institute of Health and Welfare (AIHW) has repeatedly flagged that there is a real lack of information on how the experience of disability and support services varies by location, or for groups with intersecting characteristics. This includes First Nations people with disability, people with disability from culturally and linguistically diverse backgrounds, people with disability living in remote locations and people with disability who are LGBTQIA+SB.[2693]

Failure to collect, analyse and meaningfully report on intersectional data characteristics excludes a significant proportion of people with disability and prevents progress towards a more inclusive and accessible society.

> *"Collecting and reporting on data that is broken down by participant characteristics at all points of interaction with the NDIS, to understand and address unmet need effectively. For example, the NDIS Quarterly Reports provide data on participant characteristics, but gender and LGBTIQA+ identities are not included. The Reports also provide the number of complaints and incidents reported, but no information on the participant characteristics associated with that data. We know that the participants who experience overlapping forms of disadvantage are at the greatest risk of harm within service settings." - Co-Group Report for the NDIS Review Panel (see Appendix B)*

Limited applications of intersectionality across all aspects of the ADS have resulted in significant gaps in the associated Outcomes Framework and implementation reporting to collect, monitor and provide insightful analyse on intersectional cohorts. This in turn undermines governments' commitment to First Nations people under the National Agreement on Closing the Gap and the Guiding Principles of the ADS.

5.6.1. First Nations data collection, analysis and reporting also needs to be intersectional

Ensuring there is adequate and intersectional (inclusive of gender, sexuality, geography and age) First Nations data collection and reporting across the Scheme, the ADS and the broader disability ecosystem is critical to making progress towards Closing the Gap.

The National Agreement on Closing the Gap, committed to by all Australian Governments, is built around four Priority Reforms that set the foundations for a new way of working. These Priority Reforms must be applied across all aspects of Government policy, including the scheme, the ADS and the larger disability ecosystem.

Closing the Gap *Priority Reform Four: Shared Access to Data and Information at a Regional Level* includes the following relevant commitments inclusive of the disability ecosystem:

- Clause 70: The Parties agree that disaggregated data and information is most useful to Aboriginal and Torres Strait Islander organisations and communities to obtain a comprehensive picture of what is happening in their communities and make decisions about their futures.
- Clause 71 (b): Governments agree to provide Aboriginal and Torres Strait Islander communities and organisations access to the same data and information on which any decisions are made, subject to meeting privacy requirements, and ensuring data security and integrity.

- Clause 71 (d): Aboriginal and Torres Strait Islander communities and organisations are supported by governments to build capability and expertise in collecting, using and interpreting data in a meaningful way.

Targeted approaches to building capacity and capability in this area should be a key consideration of a future national strategy for First Nations (see Action 2.10).

5.6.2. Efforts towards understanding the experiences of women and LGBTIQA+SB people with disability need to be accelerated.

Disability data disaggregated by gender and sexuality is critical to understanding need and experiences of people with disability (see Action 1.6). However, current data on gender and sexual identities is poor, contributing to critical knowledge gaps. Where we do have data on LGBTIQA+SB communities (while not population representative) it shows that over a third of survey respondents' self-report disability or long-term health conditions (majority profound or severe).[2694]

Despite this prevalence the SDAC in its current form does not collect data on gender or sexual diversity, meaning it does not capture disability prevalence in LGBTIQA+SB communities and cannot be used to understanding this significant intersectional population group. Further, the NDIA's quarterly reports do not currently include LGBTIQA+SB data.

> "Inadequate data collection practices perpetuate a cycle of invisibility. As data informs evidence-based policy, this exclusion of LGBTI people with disability can lead to adverse public policy outcomes that fail to address the unique needs and experiences of LGBTI people with disability." – *LGBTIQ+ Health Australia – Response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*[2695]

There are limited applications of gender disaggregation across all aspects of NDIA's reporting. Some Disability Representative Organisations have expressed concern that failure to enact this 'gender mainstreaming' across the scheme is impacting full realisation of Article 6 of the UNCRPD which includes:[2696]

- Respect, protect and fulfil the rights of women with disabilities.
- Take measures to ensure women with disabilities can access 'the full and equal enjoyment - of all human rights and fundamental freedoms'.
- 'Systematically mainstream' the interests and rights of women and girls with disabilities in national and sectoral action plans, strategies and policies.
- Take targeted and monitored action aimed specifically at women with disabilities.

To be most successful, gender should be considered through an intersectional lens, meaning that gender and sexuality markers will also need to be applied across First Nations and culturally and linguistically diverse data analysis and reporting.

5.6.3. Intersectional data and reporting gaps undermine our efforts to create a more accessible, inclusive and equitable society

When we prioritise the needs of community members that face multiple and intersecting forms of discrimination the entire system becomes more responsive to all people with disability. To address intersectionality and prioritise future reforms, we need to understand the current state, our commitments, investments and what affects these are or are not having on discrete population groups. To do this we need to effectively measure and monitor the outcomes of all people with disability against intersectional characteristics.

Intersectional data approaches will enable the production of insights that can be used to inform targeted advocacy, investments and hold governments and service providers to account for progression against commitments and outcomes for all people with disability.

5.6.4. Action and Implementation Details

Action 23.5: The Australian Government should ensure that all disability reporting mechanisms facilitate the collection, analysis and publication of intersectional indicators

All people with disability should be able to easily access and understand information that is relevant to them. This means that all data and reporting mechanisms across the disability ecosystem must begin collecting, reporting and publishing against intersectional characteristics including First Nations, culturally, linguistically and racially diverse, LGBTIQA+SB, gender and age as a minimum standard. This approach should be taken across the National Disability Insurance Agency, National Disability Data Assest (NDDA), ADS and the future Australian Bureau of Statistics' Survey of Disability, Ageing and Carers (including population data, NDIS participants and complaint, government investments, outcome measurements and implementation tracking) (see Action 23.4). Where data is not collected or isn't able to be published, a gap should be publicly identified along with a commitment to develop mechanisms to address the gap, through the appropriate data improvement plans. Funded efforts should also be made to adopt this minimum standard across the disability ecosystem including the NDDA.

Implementation detail:

- The Department of Social Services (DSS) should accelerate their commitment to Diversity and Intersectionality under the ADS Data Improvement Plan by leading a review of all data disability data collection mechanisms in partnership with external agencies (where needed) for the presence of intersectional data indicators.

  - Where gaps are identified a time-limited commitment to addressing this gap should be included in the appropriate data improvement plans.

- Intersectional data collection mechanisms should be reviewed and developed in partnership with the relevant community to determine the most appropriate way to request, record and analysis this information into the future.

- The National Disability Insurance Agency (NDIA) should begin analysing and publicly reporting on intersectional data (where available). This should include the practice of 'mainstreaming' gendered data across all aspects of collection, analysis and reporting including participants, complaints, critical incidents, review decisions, participant dashboards across non-Indigenous, First Nations, LGBTIQA+SB and culturally, linguistically and racially diverse population groups.

  - Intersectional data gaps should be identified and publicly noted where this information is not available. The appropriate action to remedy these gaps should be included and prioritised in the relevant data improvement plans.

- DSS should amend all ADS reporting templates to include reporting on initiatives that are tailored to intersectional needs by the populations groups outlined above. Only initiatives achieved in partnership with or inclusive of community-led aspects in design, delivery and evaluation should be included against these population groups.

- The NDIA should accelerate their commitment to 'Enhancing data collection and evaluation' for LGBTIQA+SB peoples by mapping data gaps for this core cohort. Where possible intersectional analysis should be undertaken and published as a standard practice. This includes the addition of LGBTIQA+SB breakdowns to the Quarterly Reports.

- The DSS and Australian Institute of Health and Welfare should work together to ensure that reporting against all outcomes areas of the ADS Outcomes Framework is broken down by intersectional population groups. This should be presented in a way that relevant to communities and policy makers.

- The DSS should work in partnership with relevant Australian Government data agencies to mature their intersectional reporting practices to ensure that distinct communities can understand their outcomes through an intersectional lens. This means that data on non-Indigenous, First Nations and culturally, linguistically and racially diverse people with disability is also broken down and published by gender and LGBTIQA+SB status. Where this is not possible this should be clearly noted (for example, sampling errors, privacy concerns etc.).

- DSS should work with states and territories to prioritise improvements to the quality and collection of intersectional data where needed in the relevant datasets that feed into the NDDA.

Chapter 7: Sustainability

1. Key messages

- The NDIS provides comprehensive disability insurance to all Australians, today and into the future, for the risk or costs associated with a significant and permanent disability. It also supports early intervention for children experiencing developmental delay and disability.
- Prior to the NDIS, government funded specialist disability systems supported many people with the most significant disabilities. However, there were also substantial levels of unmet need. Disability insurance was underprovided by public and private disability insurance schemes.
- We all benefit from the disability insurance provided by the NDIS, even if we do not 'make a claim'. The costs associated with the NDIS are better regarded as an insurance premium, rather than a welfare payment.
- This is not to downplay the fact that the NDIS has important wellbeing objectives by providing people with disability and their family members with greater capabilities to lead lives they value. The scheme promotes the fundamental human rights of people with disability by providing choice and control to participants. The scheme also supports higher levels of participation in the social and economic life of the community. This benefits our whole nation and should rightly be celebrated.
- However, it is also important to acknowledge one of the key objectives of this Review, as set out in its Terms of Reference, is to ensure the sustainability of the NDIS for future generations. Sustainability is about more than costs. We consider it should take into account scheme cost, benefits, spending quality, and value for money.
- In addition to the significant insurance value of the NDIS for all Australians, we have found evidence indicating it is providing many of the initially intended wellbeing and economic benefits to participants, their family members and supporters.
- The entire community also benefits from the higher level of inclusion of people with disability into the fabric of the community and economy.
- The benefits of the NDIS are evident across multiple sources, including submissions to the Review, reporting from the National Disability Insurance Agency, the outcomes framework, surveys and analysis of administrative datasets. However, based on our investigations and feedback, we also believe the NDIS could be delivering better value to participants and the broader community in many areas.
- We have investigated known and emerging cost pressures facing the scheme and believe the scheme can continue to provide the same or greater benefits with more sustainable spending.
- Our findings and recommendations provide a blueprint for a healthier NDIS. One that is sustainable for the future. Our recommendations – in response to the three key objectives in our Terms of Reference – seek to respond to underlying cost drivers within the scheme, while also ensuring improved participant experiences and outcomes and restoring trust and confidence in the NDIS.
- We do not view these objectives as being irreconcilable or mutually exclusive. Rather we believe that improving participant experiences and outcomes, and refocusing the scheme on its

originally proposed design principles and objectives will help address sustainability pressures within the scheme.

- In this regard, our recommendations to help improve scheme sustainability are focused on targeted, evidence-based reforms to how reasonable and necessary supports are provided to people with disability within the NDIS and in the surrounding disability support ecosystem. These recommendations also simultaneously ensure equity between people with disability who are eligible for the NDIS and those who are not. Foundational supports are an essential foundation for an ordinary and inclusive life for all people with disability.

- Through careful analysis of scheme cost drivers, and their underlying sources, we have found there is no quick fix or easy solution to managing scheme costs so that they consistently maximise scheme value to participants, their families, and the broader Australian community.

- We are also mindful that current data gaps make measuring what matters in the NDIS difficult. We have proposed a range of actions to improve data quality, availability and linkage along with research and evaluation infrastructure. If implemented, our reforms will address these knowledge limitations and inform a more evidence-informed approach to disability policy and support a sustainable NDIS into the future.

- The Review has examined the potential impact of our recommendations on scheme projections. Together, they are a blueprint for an equitable and sustainable NDIS and disability ecosystem. If implemented together, we are confident our reforms will secure the future of the scheme and meet National Cabinet's NDIS Financial Sustainability Framework annual growth target in total costs of the NDIS of no more than 8 per cent by 1 July 2026 with further moderation of growth over time.

- By the time the reforms mature in 2032-33, cost growth in the scheme will have gradually moderated and will be within the implied target of $87 billion in 2032-33.

2. The original vision for the NDIS

2.1. In 2011 the Productivity Commission recommended establishing the NDIS

The 2011 Productivity Commission Inquiry into Disability and Care Support found the previous legacy disability support systems administered by all governments in Australia were "underfunded, unfair, fragmented, and inefficient."[2697] Supports were rationed to people with disability with the most acute needs and led to long waiting lists, and poor participant, carer and family experiences.[2698]

The Productivity Commission found the system suffered from the 'postcode lottery' resulting in people with similar levels of disability receiving different levels of supports, choice and control simply based on where they lived.[2699] They also concluded that the old disability system was crisis-based and in a 'death spiral' as it was restricted to supporting those with the most critical and urgent support needs, rather than investing in people with disability and building their capacity.

The Productivity Commission recommended a completely new system, the NDIS, to address these shortcomings.[2700] The scheme would provide individualised supports to people with disability while

also providing comprehensive insurance for all Australians in case they are born with a disability or acquire a disability before the age of 65.

The insurance principle was central to the tenet that while most people may not need the NDIS, the system would provide reasonable and necessary support if needed for every Australian. The annual 'cost' of the NDIS is the premium that taxpayers collectively pay for this insurance.

In providing better supports for participants, the NDIS would address missing or incomplete markets for disability insurance, and address insurance market failures due to adverse selection and underinsurance against low probability, high-cost events. Given the significant additional costs associated with disability, as well as the inadequacy of disability insurance and supports prior to the NDIS, the Productivity Commission estimated these economic benefits would be substantial and would accrue to all Australians, today and into the future.

The Productivity Commission recommended a national scheme to ensure greater consistency and end the 'postcode lottery'. The scheme would be funded by all governments. National standards and entitlements would provide consistent and predictable levels of support for participants no matter where they lived and if they moved. Benefits would then be 'portable'.

The use of insurance principles would incentivise governments to take an investment-based approach to funding and put an end to the crisis-based approach. There would be significant financial incentives for governments, as well as new supporting governance infrastructure, to ensure disability supports were beneficial, safe and cost-effective. The scheme would also invest in time-limited early intervention and capacity building supports to help people be more independent and connected, therefore reducing the need for more intensive supports for some people over time and supporting long-run sustainability.[2701]

The NDIS was designed around providing greater choice and control to its participants using a market-based approach to drive innovation and efficiency. NDIS eligibility assessments were intended to identify support needs, with Local Area Coordinators providing referrals to appropriate supports both within and outside the NDIS as required. Local Area Coordinators were also intended to provide unbiased advice to people with disability and their family members on best practice supports, and suitable providers to help participants make evidence-informed choices. Participants would have greater choice over their preferred disability supports and providers. The NDIS would encourage people with disability to set short and longer-term goals for community and economic inclusion and participation, and to build their capabilities to achieve these goals.[2702]

The Productivity Commission estimated a doubling of funding was required to address chronic underfunding to improve certainty and sustainability in the provision of disability supports.[2703] The increased funding would incorporate existing disability funding from states and territories, with additional funding sourced from the Australian Government given its greater revenue raising capacity. The Productivity Commission viewed greater investment in early interventions to be essential for a sustainable disability support system.

The Productivity Commission also saw the NDIS as a component of the broader disability system and emphasised the importance of building the NDIS on the firm foundations of what it called 'Tier

2' supports for all people with disability – what we have reconceptualised as foundational disability supports. Its blueprint required Tier 2 supports – information, referral, web services and community engagement – to work in tandem with the NDIS rather than the NDIS replacing them.[2704]

Individualised budgets through the NDIS were only envisaged for a small proportion of people with the highest support needs and greatest capacity to benefit from them. There was an expectation that foundational supports or mainstream services would meet the support needs of most people with disability and become more inclusive and supportive over time. Governments would also continue to provide a range of other disability supports, including home based community care services for those people with lower or episodic support needs. Chapter 2 outlines the importance of strengthening these supports to improve outcomes for people with disability and improve NDIS sustainability.

A fully functioning NDIS would improve and centralise data collection to support evidence-based decision-making. The data would allow measurement of scheme and provider performance, and evaluate if participant goals, outcomes and benefits were being met by supports. Combined with more and better linked administrative data, the National Disability Insurance Agency (NDIA) research function was intended to help improve the evidence base underpinning disability policy and supports, including interactions between the NDIS and other supports.[2705]

2.2. In 2017 the Productivity Commission reported on the costs of the NDIS

The Productivity Commission's 2017 report on NDIS Costs was delivered four years after trials for the scheme had commenced rolling out across the country. The findings of the report were to inform the final design and funding arrangements for the 'full scheme' after completion of transition arrangements. The report also considered whether the NDIS was delivering the benefits initially envisioned in 2011 and if there were early signs of emerging cost pressures.[2706]

Although the scheme was still in its early stages, with around 90,000 participants, the Productivity Commission found some evidence the scheme was improving outcomes for people with disability, which had been identified through survey data from the NDIS Outcomes Framework, and a qualitative evaluation by the National Institute of Labour Studies.[2707] These improvements included participants receiving more disability supports and experiencing greater choice and control.[2708] The report also noted a range of uncertainties regarding predicting scheme costs. This included the initially slower than expected take up rates for participants at the start of transitioning to the NDIS, and later, effort by the NDIA to get participants on board as quickly as possible at the expense of investing in quality planning processes, developing markets and supporting infrastructure.[2709]

The Productivity Commission identified key emerging challenges which if left unaddressed had the potential to lead to poorer participant experiences and outcomes. In particular, achieving the required workforce growth in the disability support sector was a critical challenge to meeting participant needs. The Productivity Commission also identified five emerging cost pressures that had the potential to undermine scheme sustainability:

- Higher than expected numbers of children entering the scheme.
- Lower than expected participants (particularly children) exiting the scheme.
- No slowing in the number of potential participants approaching the scheme.
- Increasing package costs over and above impacts of inflation and ageing.
- A mismatch between benchmark package costs and actual package costs.[2710]

The Productivity Commission highlighted the importance of further developing the scheme interface with other service systems and the need for more investment in Tier 2 supports to ensure the sustainability of the NDIS.[2711]

2.3. Our Review is the first comprehensive review of the scheme since the completion of the national rollout of the NDIS in 2020

Our Review is the first comprehensive assessment of the health of the scheme since the national rollout was completed on 1 July 2020. Our assessment focuses on determining if the scheme is meeting its intended purposes, and understanding the benefits it provides for participants, their family members, and the community more broadly.

The NDIS is a scheme that fills a gap in the Australian economy and safety net, by providing comprehensive insurance to all Australians who might incur a severe and permanent disability before the age of 65. Such insurance is not provided by the market and the government has stepped in to correct this market failure. This benefits all Australians who could face disability at some stage in the future - not just those with who currently have a disability.

As an insurance scheme for all Australians, NDIS costs are a premium that all Australians pay for comprehensive disability insurance. Given the substantial and, in many cases unaffordable additional costs associated with disability faced by people with a disability and their families and supporters, the value of this insurance is likely to be highly significant.

3. Assessing the benefits of the NDIS

3.1. Our approach considers both the benefits and costs of the scheme

From the beginning we have taken the view that sustainability is about more than just costs alone. Sustainability is an essential pre-condition for better participant experiences and restoring trust and confidence in the NDIS. Dr Simon Duffy, a British social policy reformer, and Dr Mark Brown, in a report reviewing the NDIS commissioned by the Disability Advocacy Network Australia, came to the same conclusion. They warned:

> *"The most important problem is that the growing cost of the NDIS will eventually break the bond of trust between people with disabilities and society as a whole. Unless these problems are addressed economic pressure will almost certainly undermine political support for the NDIS. In fact a strong case can be made for treating sustainability as a fundamental foundation of any system of human rights."- Dr Simon Duffy and Dr Mark Brown[2712]*

Being an insurance scheme at its core, the primary objective of the NDIS is to deliver adequate disability funding and support for Australians who need it. However, the desirability of providing

adequate disability insurance does not negate the need to consider the quality of disability supports and spending within the scheme.

We were particularly interested in gaining a fuller understanding of progress the scheme is making to deliver on the intended wellbeing and other benefits to people with disability, their families, and the broader community. We looked at the impact of the NDIS, including its value for money, as a starting point to assess how to improve participant experience in the scheme and ensure its sustainability into the future. We used the best available data and information to develop a benchmark for NDIS performance against which future progress can be assessed.

Sustainability also demands that the NDIS should deliver outcomes and benefits to participants and the broader community in a cost-effective manner. Being able to more clearly link outcomes and benefits to investments in particular supports will be critical to delivering better outcomes to participants and a more sustainable scheme in the future.

Fundamentally, the NDIS cannot be treated like a limitless resource, and governments need to balance other funding priorities. The NDIS also sits within a broader ecosystem of disability supports so there needs to be a balance between funding supports for the approximately 1 in 50 Australians who were intended to be eligible for an individualised NDIS package and supports for the approximately 1 in 5 Australians with a disability regardless of their eligibility for the NDIS.[2713]

Our approach to considering sustainability is consistent with the Insurance Principles and Financial Sustainability Manual of the NDIA that defines its responsibility for managing financial sustainability as:

> *"simultaneously seeking to maximise the likelihood that:*
>
> - *the scheme is successful on the balance of objective measures and projections of economic & social participation and independence, and on participants' views that they are getting enough money to buy enough high-quality goods and services to allow them reasonable access to life opportunities – that is reasonable and necessary supports; and*
>
> - *contributors think that the cost is and will continue to be affordable, under control, represents value for money and, therefore, remain willing to contribute." - NDIA[2714]*

Further, we also fully agree with the *Insurance Principles* framework that establishes an objective for the NDIS to:

> *"invest in research and innovation to support its long-term approach and objective of social and economic participation, and independence and self-management, for participants, and*
>
> *support the development of community capability and social capital so as to provide an efficient, outcomes-focused operational framework and local area coordination and a support sector which providers a high quality service and respects participant social and economic participation and independence". - NDIA[2715]*

3.2. We have used qualitative data from submissions and quantitative data to guide our analysis

Our broader analysis of NDIS benefits included reviewing feedback from submissions to the Review, analysis of evidence from longitudinal surveys and linked administrative datasets. This allowed us to test if findings were consistent between the different methods.

Our analysis suggests that the NDIS is delivering many of its originally intended benefits for people with disability and their families. As anticipated, these benefits have predominantly been non-market benefits, including through improved life satisfaction for participants and carers. There is also some evidence of market benefits such as reduced costs in hospital use and higher levels of carer employment.

Due to challenges concerning data quality, availability and linkage, and a range of conceptual and methodological issues, it is likely that aggregate benefits are significantly underestimated and fall well short of providing a comprehensive or fair assessment of scheme benefits in aggregate. These observations have informed our recommendations about the urgent need to improve data quality, availability, linkage and use and to strengthen supporting data, research and evaluation institutional architecture.

3.3. Submissions to the Review indicated that the NDIS is supporting some participants well

The Review received 3,976 submissions from a wide range of stakeholders, including participants, their families, service providers, advocacy groups and government agencies. Submissions were also received from people with disability who are not participants in the scheme.

In these submissions, participants shared their lived experience with the NDIS and their insights, ideas and solutions. Many acknowledged the positive and meaningful improvements the NDIS has made to their lives. Most submissions and consultations focused on suggested areas of improvement for the NDIS rather than existing benefits.

The greatest benefit identified in the submissions received was that the NDIS provides adequate and flexible funding.[2716] This supports the notion that the NDIS has provided greater choice and control for many.

> *"NDIS has opened up a world of opportunities that was otherwise unaffordable to my son who is on the autism spectrum and minimally verbal. The improvement as a result of funded intervention when he was younger and now funded support to keep him busy as a teenager has enabled him to live with dignity and my family to live with disability. Without the NDIS, I am sure my son would be just another lifelong ward of the state." – Carer[2717]*

Several submissions indicated the NDIS provides participants and families with the capacity to change their lives for the better.[2718] A provider in their submission highlighted the transformative nature of NDIS supports for people with disability:

"There are people out there who have never had support in the past, but now do and it has changed their lives. People who are under 65 with significant disabilities are being supported in the community and not in nursing homes, a game changer for them. People are actually building capacity, maybe not as much as the NDIS would like, but its progress for them, which is amazing. People who have lived for years in mental health institutions are now able to live in the community, how good is that! The opportunities it has given some people is life changing." – Provider[2719]

Many submissions noted the importance of frontline workers and service providers and the high quality supports provided.[2720] One submission noted frontline workers have improved the quality of life enjoyed by her sister which would not have been possible without the NDIS:

"The NDIS has been absolutely wonderful for my sister… She loves to go out for coffee, spend time with her peers in group settings where she can participate by being helped by carers with activities such as art. She has been to concerts, including a trip to Sydney to see Disney On Ice and carers constantly try to think of different things to do with her, including attempting to try swimming. If it wasn't for the NDIS, my sister quite simply wouldn't have a life at all, she would be sitting in a chair in the care facility she lives in doing very little". – Carer[2721]

In addition, submissions also noted the NDIS has increased capacity building supports, which has helped participants achieve their goals, increase their independence, and empowered them to engage more in community and family life.[2722]

"The NDIS helps me live more independently and confidently. I have significant pain and limitations with my disability and the NDIS allows me to access services that help me participate in daily life - relationships, work, recreation, rehabilitation and wellness activities." – Participant[2723]

We also found positive participant and carer impacts from our quantitative analysis. We undertook exploratory analysis using the Australian Government's Person Level Integrated Data Asset (PLIDA) data to gain insights on the impact of the NDIS on participant and carer lives. By linking information on health, education, government payments, income and taxation, employment, disability and the Census over time, we were able to better understand the impact of the NDIS on participants and family member income, use of subsidised healthcare services, and psychological wellbeing.

Overall, our analysis suggests the NDIS is starting to deliver some of the envisaged benefits for people with disability and their families. While these benefits are modest at this stage, they are likely to represent a relatively conservative, lower-bounds estimate of relevant NDIS net benefits. The full scheme has only been operating for three years and benefits will continue to increase over time, given the lifetime approach to participant support. Further detail of this analysis is outlined at Appendix C.

3.4. We found evidence that the NDIS is providing benefits utilising multiple survey and administrative datasets

Our review of survey data from the NDIA and the PLIDA longitudinal survey shows important signs that the NDIS is delivering on many of its originally envisioned benefits. However, a stronger evidence base is required to fully understand the scheme's impact.

When the Productivity Commission in 2011 first explained why the NDIS was needed, it emphasised the high risk of social isolation and low levels of wellbeing that people with disability are likely to face, as well as higher levels of disadvantage in education and employment.[2724] It anticipated the key benefits of the NDIS would include improved wellbeing for people with disability and their families, efficiency gains in the provision of disability services, savings to other government services, improved economic participation for people with disability and their families and associated fiscal benefits through reduced spending on welfare and other government services.

While we note survey data varies in its comprehensiveness, it is significant to see participants and family members reporting many of the benefits foreseen by the Productivity Commission.

3.5. The NDIS Outcomes Framework shows strong improvements in participant outcomes over five years

The NDIS Outcomes Framework is a survey administered by the NDIA that provides insights on the outcomes of participants, their families and carers. It is longitudinal and there are two versions: the Short Form which is completed by all participants as part of planning and a Long Form, which is completed annually by a sample of participants. In both versions, a family member or carer is also interviewed, if available. Outcome indicators captured by the survey relate to a number of different domains including choice and control, daily living, work, lifelong learning, home, health and wellbeing, relationships, and social, community and civic participation.

The 30 June 2022 Outcomes Framework report provided a detailed summary on outcomes that are improving and those that are deteriorating. Based on survey responses, participants are accessing more learning opportunities and specialist services, as well as connecting more in the community and exercising more choice and control in their lives.[2725] Families and carers are getting more opportunities to participate in permanent employment.[2726] Figure 172 below shows strong outcomes for participants who have been in the scheme for five years, using data from the NDIS Outcomes Framework.

Adults and Adolescents

The strongest life improvements reported by adult and adolescent participants (aged 15 and over) relate to increased self-determination. In the first Long Form survey report (July-December 2016), for adult and adolescent participants, 52.6 per cent had opportunities to have new experiences, 57.9 per cent chose how they spent their free time and 71.1 per cent chose whom they lived with.[2727] At the fifth yearly interview, these indicators showed significant improvement, increasing

respectively by 25.0 percentage points (to 77.6 per cent), 19.7 percentage points (to 77.6 per cent) and 14.5 percentage points (to 85.6 per cent).

Children

For participants who are children, the strongest improvement in outcomes reported by parents and carers relate to stronger engagement in family and community life and access to services. In the first survey report (at baseline, that is, scheme entry), 66.7 per cent of parents and carers of child participants said their child uses specialist services, 74.5 per cent reported their child fits well into everyday family life and 42.4 per cent reported their child becoming more independent.[2728]

After five years in the scheme, these responses increased respectively by 29.6 percentage points (to 96.3 per cent), by 13.9 percentage points (to 88.4 per cent) and 10.9 percentage points (to 53.3 per cent).

Conversely, we also have seen poorer outcomes. 36.9 per cent of children attend or have attended school in a mainstream class at their five year review – compared to 44.1 per cent at scheme entry (a reduction of 7.2 percentage points), noting that participation is generally higher for younger children and decreases as they age.[2729] 31 per cent of children participated in activities after school or on weekends with friends and/or in mainstream programs at their five year review – compared to 34 per cent at scheme entry (a reduction of 3 percentage points).[2730]

Families and carers

Families and carers report they are more supported and are increasingly able to maintain employment. In the first survey report, 26.7 per cent agreed services helped them to better care for their family member with disability, 40.8 percent agreed they feel more confident about the future of their family member with disability and 45.6 per cent were in a paid job.[2731] After five years in the scheme, these responses increased respectively by 54.6 percentage points (to 81.3 per cent), by 34.2 percentage points (to 75.0 per cent) and 9.7 percentage points (to 55.3 per cent).

There are also additional questions which arise from a deeper analysis of current data. In the same report, families and carers indicated that compared to when they entered their scheme:

- Their rating of their health declines.
- They have a declining number of people they can ask for practical help.
- There is little change in the number of people from whom they can ask for emotional support.[2732]

Families or carers who rate their health as excellent, very good or good had declined 13.1 percentage points from the baseline by the fifth review.[2733]

19.2 per cent of families can engage in social interactions and community life as much as they want at the five year review – compared to 28.1 per cent at scheme entry (a decrease of 8.9 percentage points). Importantly, 96.6 per cent of those unable to engage in the community as much as they would like after five years in the scheme say the situation with their child is a barrier to engaging more.[2734]

31.8 per cent of families have people they can ask for practical help as they need at the five year review – compared to 40.4 per cent at scheme entry (a reduction of 8.6 percentage points). 38.8 per cent of families have friends they can see as often as they would like at the five year review – compared to 44.5 per cent at scheme entry (a reduction of 5.6 percentage points).[2735]

Figure 172: What do participants, families and carers say about how the NDIS improves their lives?[2736]

What do participants, families and carers say about the NDIS?

As per the NDIS Outcomes Framework report at baseline

What do parents and carers say about the scheme's impact?

Nearly 10 out of 10 parents/carers say specialist services assist their child's development. An increase from 7 out of 10 at baseline.

9 out of 10 parents/carers say that their child fits well into family life. An increase from 8 out of 10 at baseline.

5 out of 10 parents/carers say their child is more independent. An increase from 4 out 10 at baseline.

What do families and carers say?

8 out of 10 families/carers agree services and supports helped them better care for a participant. An increase from 3 out of 10 at baseline.

8 out of 10 families/carers agree they feel more confident about the future of their family with disability under the NDIS. An increase from 4 out of 10 at baseline.

6 out of 10 families/carers were in a paid job. An increase from 5 out of 10 at baseline.

What do adults and adolescent participants (aged 15 and over) say?

8 out of 10 participants say they have opportunities to try new things and have new experiences. An increase from 5 out of 10 at baseline.

8 out of 10 participants say they choose how to spend their free time. An increase from 6 out of 10 at baseline.

9 out of 10 employed participants say they chose whom they lived with. An increase from 7 out of 10 at baseline.

While the NDIS Outcomes Framework report provides useful insights into participant and family or carer experiences and wellbeing, some of the outcomes are qualitative in nature, coverage is not

universal, and responses are voluntary for the Long Form survey which can affect the representativeness of the data reported.

It is also difficult to differentiate whether changes in participant and family wellbeing were due to NDIS funded supports or due to other policies or factors. Previous reports (for example, the 30 June 2020 reports) did link outcomes to plan budgets, support types and time in the scheme. There are also some "deep dive" reports, for example, on employment and health and wellbeing outcomes, which also model outcomes in relation to supports and time in the scheme.

The NDIA is developing additional methods to link expenditure and support types to outcomes through the Investment Effectiveness Program, which should provide a better understanding of the links between NDIS goal setting, services, costs and benefits.

The NDIA has also partnered with the Monash University Centre for Health Economics to develop a new wellbeing index for all people with disabilities aged 15 and above, including NDIS participants. The index is an evidence-based measurement of wellbeing of people with disability and includes life aspects aligned with the NDIS Outcomes Framework and Australia's Disability Strategy. The index will provide a valuable reference point for determining the impact of the disability services within and outside the NDIS for people with a disability, and support prioritising resources to achieve the best impact.

Stakeholders have also proposed that questions in the NDIS Outcomes Framework need to be enhanced to ensure all people with disability understand what is being asked. Scope, a large disability service provider, suggested in their submission that the NDIS Outcomes Framework should use the revised Outcomes and Impact Scale (O&IS-R), which is a self-reporting survey where people with disability report service impact based on nine life domains. Researchers have found that the O&IS-R is accessible to a diverse range of people with disability.[2737] We also discuss our related recommendations for an NDIS outcomes framework in Chapter 6.

3.6.   Analysis of the Household, Income and Labour Dynamics in Australia (HILDA) longitudinal survey also supports the finding that the NDIS is improving lives

We commissioned Taylor Fry, an analytical and actuarial consulting firm, to examine data collected in the HILDA longitudinal survey to try and identify some scheme benefits in addition to our own analysis, as part of its work on estimating scheme net costs and net benefits.[2738] Taylor Fry looked at responses from NDIS participants, carers and non-carers living in the same household over the last four waves of HILDA, across different outcome domains. Taylor Fry used statistical analysis to measure the impact of the NDIS on these domains.

The analysis revealed the NDIS improved carers' lives on several outcomes including life satisfaction, financial security and employment status. These findings align with feedback from submissions to the Review and results from the NDIS Outcomes Framework report and demonstrate the broader benefits of the NDIS.

4. The scheme continues to face a range of sustainability challenges

The Productivity Commission in its 2017 report identified five key emerging trends placing pressure on costs to the scheme:

- Higher than expected number of children entering the scheme.
- Lower than expected participants (particularly children) exiting the scheme.
- No slowing in the number of potential participants approaching the scheme.
- Increasing package costs over and above impacts of inflation and ageing.
- A mismatch between benchmark package costs and actual package costs.[2739]

We have found these cost pressures remain a challenge today. As they have not been addressed, meeting these challenges has become both more complicated and more pressing. We know there is not one single issue driving the growing cost pressures on the NDIS. Understanding these cost drivers, and finding ways to address their root causes, is an important part of managing the NDIS.

A trusted NDIS is one where costs are managed effectively and reliably, every dollar is spent wisely and cost growth is predictable. Because sustainability is about more than just costs, this should include consideration of the benefits and outcomes the NDIS achieves.

The Reviewing Actuary has also pointed to continuing sustainability challenges in response to the June 2023 Financial Sustainability Report, which has been published in the NDIA 2022-23 Annual Report. In writing to the Chair of the NDIA Board he notes:

> *"... caution is required. Past reports have consistently assumed that scheme experiences would moderate in the short term, yet this moderation has so far failed to materialise. As a result, projections have been increased each year since 2019. Until the assumed moderating experience shows a greater presence in the data, there remains a risk that the Baseline projection understates what might occur, in the absence of Budget initiatives. I consider this risk to be greater in the medium term.*
>
> *The Baseline projection is then reduced to allow for the initiatives set out in the May 2023 Budget. These initiatives reduce the Baseline projection by $8.5 billion over 2023 – 26. As these initiatives are subject to a co-design process, there is a material level of uncertainty regarding the impact of the initiatives on future expenses." - Australian Government Actuary* [2740]

4.1. Cost and participant projections continue to increase

As at 30 June 2023, the total number of participants in the NDIS was 610,502, and the total cost for 2022-23 was $35.1 billion.[2741] This was 3.2 per cent higher than the NDIA's 2021-22 Annual Financial Sustainability Report (AFSR) projection of $34.0 billion for 2022-23 costs.[2742] With 101,000 more participants and $8 billion in additional total costs this is significantly more than the projections made by the Productivity Commission in 2017.[2743]

There have been multiple revisions to the scheme's projected costs in the years since the 2017 Productivity Commission report, including upward revisions for three successive years from the 2019-20 AFSR to the 2021-22 AFSR.[2744] The growth and lack of predictability in NDIS costs impacts on the certainty and predictability of the scheme and has the potential to undermine public confidence and trust in the NDIS. This is why the financial sustainability of the scheme is an important consideration of this Review.

Figure 173 shows a comparison of projected total scheme payments for 2022-23, 2027-28 and 2032-33 as forecasted in the 2017 Productivity Commission Report and each subsequent AFSR. This shows how cost estimates have been revised up with each new AFSR. There is a 65 per cent projected increase between the 2017 Productivity Commission forecast and the most recent NDIA projection for 2027-28 costs. These revisions become larger over a longer period, with the Productivity Commission projection for 2032-33 of $50 billion increasing 87 per cent to $94 billion in the 2021-22 AFSR projection.

Figure 173: Projected total payments for 2022-23, 2027-28 and 2032-33[2745]
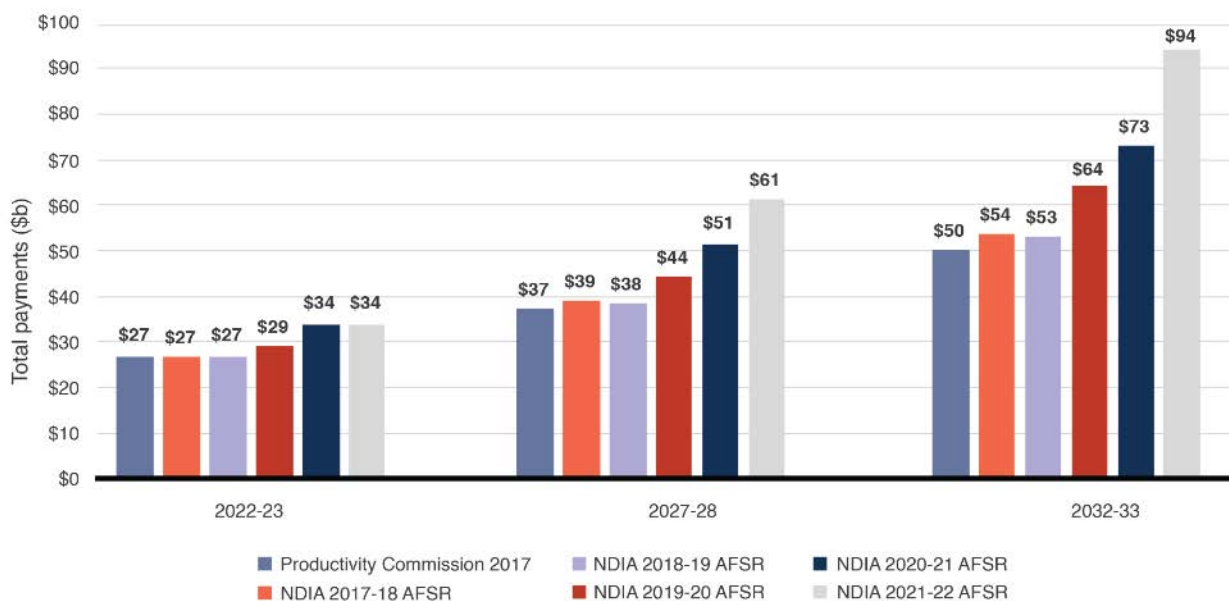
A critical factor in these forecasts is when participant numbers stabilise A critical factor in the difference between the 2017 Productivity Commission projections and the 2021-22 AFSR projections are the underlying assumptions on when participant numbers stabilise. This indicates when the scheme has reached maturity and the growth in participant numbers becomes stable to only reflect the growth in the Australian population.

The 2017 Productivity Commission report assumed the scheme would reach maturity by 2019-20, however, evidence to date suggests this has not yet happened. In the June quarter of 2023, 31,263 total access requests were made, representing a 10.2 per cent increase from the previous

quarter.[2746] Out of these access requests, 23,756 new participants joined the scheme – equivalent to a 76.0 per cent access met rate for the June 2023 quarter.[2747]

Figure 174 shows the proportion of the Australian under 65 population on the NDIS, otherwise referred to as the "participation rate". The Figure shows the actual participation rate since 2017, the 2017 Productivity Commission report's projected participation and the NDIA's latest published projection using data from the 2021-22 AFSR.

Figure 174: Historic and projected participation rates - Australians aged 0 to 64[2748]
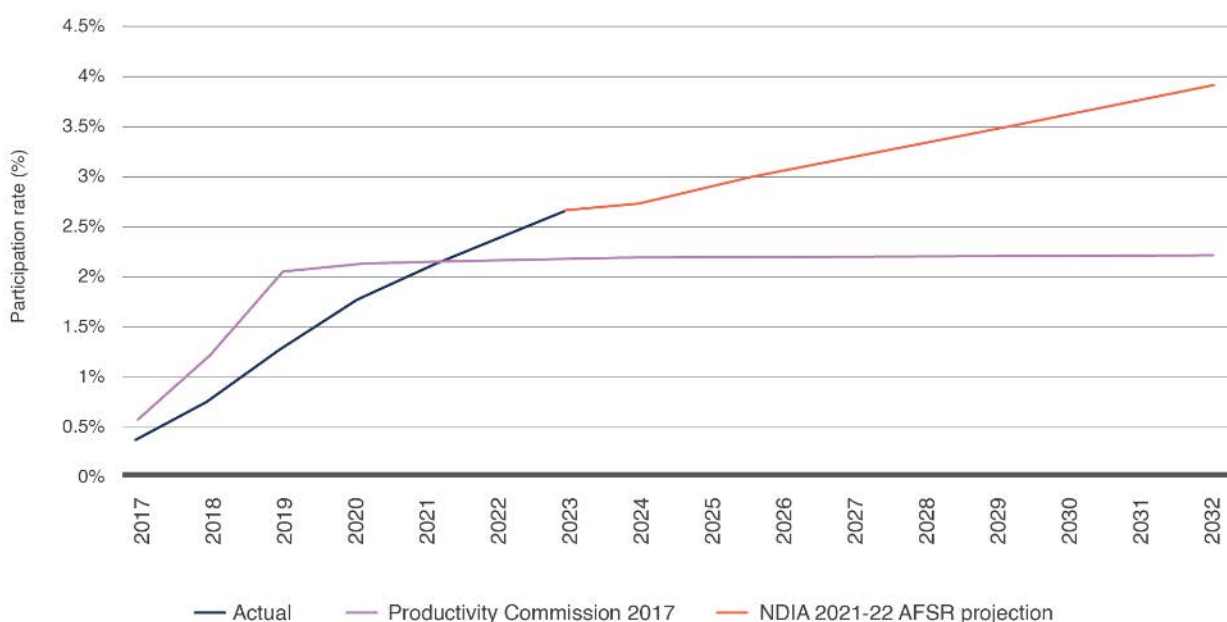
The Productivity Commission in 2017 expected the scheme would mature at 2.2 per cent of the 0 to 64 population from 2019-20 but the current evidence shows the NDIS participation has already exceeded this estimate and does not appear close to reaching maturity. The most recent 2021-22 NDIA AFSR projections estimate participant numbers will continue to grow and be nearly twice the Productivity Commission's projection, reaching 3.9 per cent of the Australian 0 to 64 population by 2032.

The projected growth in participants and the point at which the scheme is assumed to reach maturity has a direct impact on projected future scheme costs. There is still uncertainty at when maturity will be achieved with the 2023 Intergenerational Report (IGR) noting the timing of scheme maturity is still uncertain, and as a result future cost projections vary considerably.[2749]

The IGR's analysis indicates that under current settings scheme maturity is 20 years away.[2750] The IGR assumes the NDIS will reach maturity in 2043-44, at a projected cost of around 2.1 per cent of GDP.[2751] However projected scheme costs are sensitive to assumptions about participant numbers and scheme maturity, with the IGR noting that NDIS costs could vary between 2.0 per cent of GDP (early maturity) to as high as 3.2 per cent of GDP (later maturity) in 2062-63. These growth

projections are a key reason why the IGR estimates the NDIS will be the third fastest growing government payments program, after health and aged care.[2752]

The participant and cost trajectory of the scheme is part of the reason why in April 2023, National Cabinet agreed to a NDIS Financial Sustainability Framework. The Framework provides an annual growth target of 8 per cent by 1 July 2026 for scheme costs, with further moderation of growth as the scheme matures. The Australian Government made further commitments to support the sustainability of the scheme in the 2023-24 Budget, including $910 million over four years to strengthen the NDIS, including $732.9 million which is designed to improve the sustainability of the scheme.[2753]

4.2. Lack of support outside the scheme contributes to NDIS growth

The NDIS is supporting more people with disability than previously anticipated and this is a significant driver of scheme expenditure.

When the Productivity Commission designed the NDIS in 2011, it suggested most people with disability would be supported by foundational and community supports and mainstream services outside of the NDIS.[2754] This has not eventuated, and instead there is an over-reliance on the NDIS as an oasis in the desert.

This leads to poor outcomes for people with disability who are left without supports and is a key contributor to the increasing numbers of people with disability approaching the scheme. Figure 175 shows the historic changes in the number of participants each year, from July 2017 to June 2023, and then the projected participant number changes until June 2032.

Figure 175: Historic and projected change in active participants over time for years ending 30 June[2755]
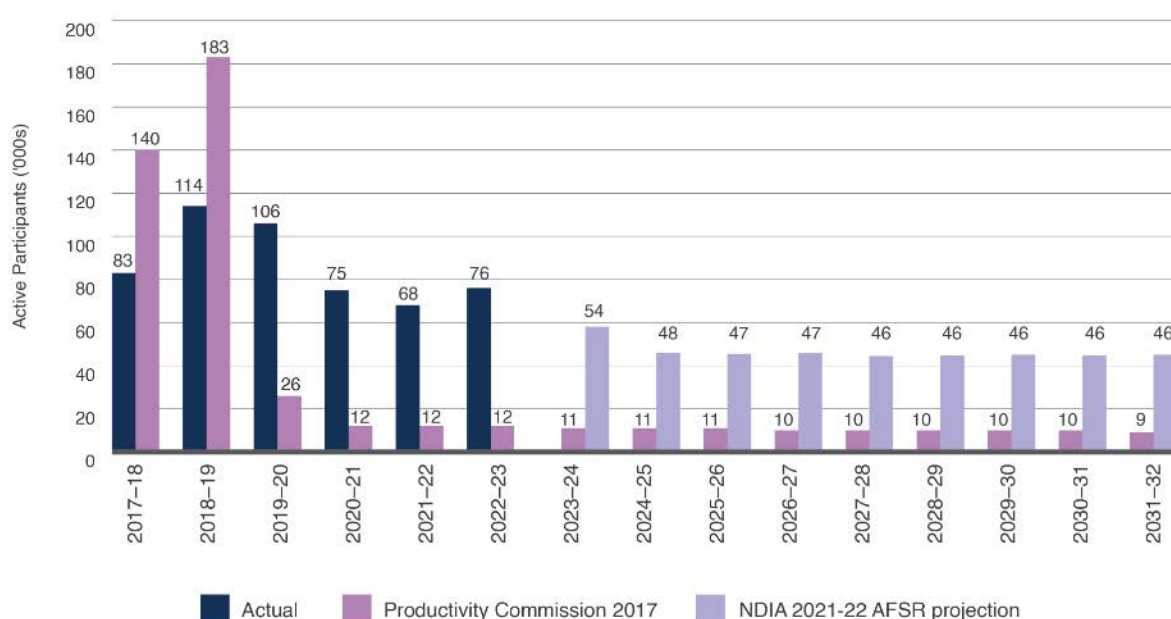
Actual changes in participants averaged around 73,000 entrants each year in the three financial years following June 2020, and the NDIA June 2023 projections still estimates around 45,000 additional participants each year for the next decade.

In its 2017 report, the Productivity Commission expected the scheme to reach maturity by 2020 with 474,000 participants.[2756] This estimate was based on 350,000 additional participants over the June 2017 to June 2020 period, before slowing down to 12,000 or less participants in each subsequent year.

While the Productivity Commission projection was higher than actual participants as of June 2020, since then the actual participant entry rate has outstripped Productivity Commission projections.

The 2017 Productivity Commission report stated the increased flow of participants can't be easily addressed by just the NDIA. It noted the NDIS relies on other supports and services available outside the scheme to be sustainable.[2757] Without these gaps being filled, people with disability will naturally seek to access the NDIS contributing to the rising projections for scheme costs.

Our analysis of the scheme experience since 2017 supports the Productivity Commission's view.

4.3. There are more children in the NDIS than expected

The NDIS has revealed a level of demand for supports for children that was not expected when the scheme came into existence. Limited supports outside the NDIS for children has created significant pressure to access the scheme. Based on what we have heard, it is not surprising parents and carers seek access to the NDIS for their children with disability and developmental concerns due to the lack of mainstream services and foundational supports. Then, they want their children to remain in the scheme. These actions are entirely rational, given current structures and incentives.

At the same time, the past decade has seen a continued rise in awareness of neurodivergence, contributing to a rise in diagnostic rates for children. The ABS's Survey of Disabilities, Ageing and Carers shows the proportion of Australians aged 0 to 19 with autism increasing from 1.0 per cent in 2009 to 2.5 per cent in 2019.[2758] This reflects a global trend of rising diagnostic rates for autism and ADHD. When combined with the 20 per cent of Australian children estimated to have a disability or developmental concern, we can see why this increase has been significant.[2759]

The impact of the increased number of children in the scheme has been dramatic. As at 30 June 2023, more than half of participants were aged 0 to 18 – or just over 313,000 children.[2760] This number is not only high compared to the initial modelling of the NDIS by the Productivity Commission in 2011, but also higher than the revised projections of the Productivity Commission in 2017. Compared to the 2017 report, there were 143,000 more active participants aged 0 to 18 in the scheme as of June 2023.[2761]

A key reason for this is due to the inclusion of developmental delay in the NDIS. Developmental delay was not originally included in the Productivity Commission design of the NDIS in their 2011 report; however, there are now 68,000 children with developmental delay in the scheme as of 30 June 2023.[2762]

In addition, the majority of children who previously entered the scheme under section 25 early intervention arrangements with a diagnosis of developmental delay have remained on the scheme via a permanent section 24 disability diagnosis.[2763] We have found once people enter the scheme, because of the lack of supports outside the scheme, they stay and are unlikely to exit.

More children entering than expected was identified by the Productivity Commission in 2017. This was based on early evidence from trial sites, where prevalence rates in Hunter and Barwon were above NDIA modelling assumptions for ages 0 to 18, including almost twice as high for children aged 5 to 9.[2764]

Since then, the Productivity Commission's projections from 2017 have been outpaced by even higher entry rates nationally (see Figure 176). Consistent with the Productivity Commission findings in 2017, the current evidence on entry rates for the 0 to 18 age cohort far exceeds initial projections. This includes 44,000 more children in the 0 to 6 age band, 72,000 more in the 7 to 14 age band, and 26,000 more in the 15 to 18 age band. Conversely, there have been fewer participants over the age of 18 than projected. For the age bands from 19 to 64 combined, there have been 37,000 fewer participants than projected.

Figure 176: Projected and actual participants by age band for 30 June 2023[2765]
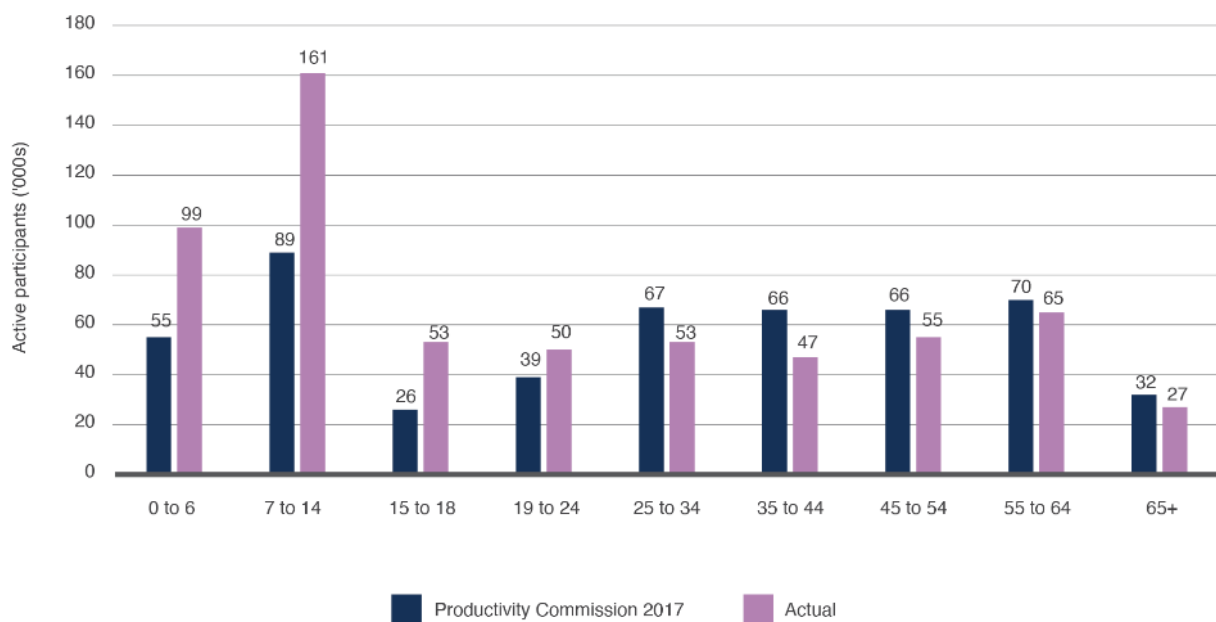
Notably, entry rates for children have been uneven across states and territories (Figure 177). Nationally, the participation rate for children is 5.1 per cent.[2766] There are two clear outliers, with Western Australia significantly lower at 3.7 per cent and South Australia significantly higher at 7.0 per cent. These coincide with different timelines for rollout – South Australia was the first location in Australia for the NDIS rollout for children aged 0 to 14, while Western Australia was the final state to transition into the NDIS. However, these differences also likely reflect local policies and community awareness.

Figure 177: Participation rate for Australians aged 0 to 18 by states and territories as at 30 June 2023[2767]

Higher than expected entry rates and lower than anticipated exit rates are contributing to higher participant projections. By June 2033, the NDIA projects 608,000 participants aged 0 to 24 – or 377,000 more participants than the Productivity Commission in 2017 (Figure 176).

This difference is made up of an increase in participants in the scheme with autism or developmental delay. The NDIA 2021-22 AFSR projections are that there will be 554,000 autistic participants and children with developmental delay by June 2032 (Figure 178). This is 407,000 more autistic participants and children with developmental delay than the Productivity Commission projected in 2017. For all other disabilities combined, the NDIA projects 9,000 more participants relative to 2017 Productivity Commission projections.

Figure 178: Projected participants by age band and disability group for 30 June 2032[2768]

Figure showing bar chart with axis "Active participants ('000s)".

Category	Productivity Commission 2017	NDIA 2021-22 AFSR projection
0 to 24	229	585
25+	372	433
Autism and developmental delay	147	554
All other disabilities	455	464

Legend: ■ Productivity Commission 2017 ■ NDIA 2021-22 AFSR projection
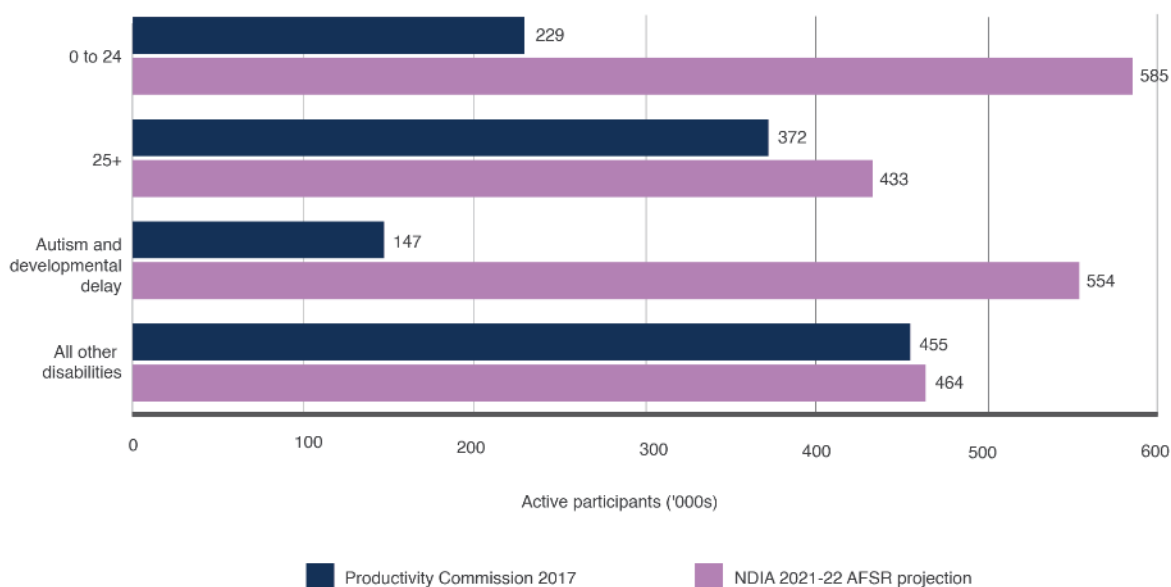
4.4.   Experience suggests early intervention is not working as intended

A key cause of more children in the NDIS than expected is the poor operationalisation of early intervention supports inside and outside the NDIS and specifically, the developmental delay pathway.

Developmental delay is a disability group in the NDIS used to identify children under the age of 6 who take longer to reach age-specific milestones, in the absence of a diagnosed condition. Children with developmental delay are admitted under section 25 early intervention criteria of the *NDIS Act 2013*.

The 2011 Productivity Commission report predicted the NDIS, like all insurance schemes, would prioritise investment in early intervention supports that potentially improve, or stabilise, functional capacity and minimise long-term costs.[2769]

The Productivity Commission believed the high costs of helping people in situations of acute need (e.g. hospitalisation) was displacing investment in early interventions that could reduce the likelihood of acute care needs arising in the first place. Under the lifetime of care and support approach of the NDIS, funding could be focused on the earlier stages of a person's disability to help improve their outcomes and reduce or stabilise future support needs.

The Productivity Commission in 2011 recommended a section of the NDIS be dedicated to an evidence-based early intervention approach built on an analysis of what worked. Early intervention supports would be subject to a cost-benefit assessment, with funding linked to evidence of these supports achieving their intended aims. Over time this would allow the NDIA to develop a more robust evidence base to underpin early intervention practices.[2770]

However, we have found early intervention has not been as effective as intended. Instead, the experience so far has been much higher entry rates than expected and insufficient evidence to suggest anticipated improvements in outcomes or reductions in support needs for early intervention participants over time – as indicated by actual exit rates being lower than expected.

As at 30 June 2023, the NDIS had 188,000 early intervention participants – far surpassing the 80,000 at maturity when originally modelled by the Productivity Commission in 2011.[2771] As a proportion of the NDIS, the Productivity Commission projected 19.5 per cent of the NDIS as early intervention participants while the current proportion is 30.8 per cent.[2772]

While it is reasonable to suggest that a larger number of children require early intervention supports than was initially anticipated by the Productivity Commission, it was also arguably reasonable to assume that the needs of more children with disability or developmental delay would be met through foundational supports rather than the NDIS.

Developmental delay is currently the largest driver of higher early intervention entries.

The 2017 Productivity Commission report used evidence from NDIS trial sites to determine higher developmental delay entry rates as a key driver of more children entering the scheme than expected. It cited evidence from the NDIS trial sites that entry rates were surpassing its initial expectation of 11,600 children with developmental delay and global developmental delay once the scheme rolled out fully.[2773]

In response to the trial site data, from 2016 the NDIA implemented the Early Childhood Early Intervention (ECEI) approach.[2774] The ECEI was designed to assist children under the age of 7 and their families achieve better long-term outcomes through accessing support services in their local community, regardless of their diagnosis, through an early childhood intervention service provider. This approach was successfully trialled in the Blue Mountains - Nepean area of NSW and was expected to help reduce the demand for support in the NDIS. The trial results suggested that cost pressures would ease, as it was expected that more children with lower support needs would have these met outside the scheme.

However the approach adopted in the Blue Mountains – Nepean area was never fully operationalised, as NDIA Early Childhood partners prioritised access requests and so, not surprisingly, the current rate of entry rate for developmental delay continues to far exceed projections. Following the Productivity Commission report in 2017, the 2017-18 AFSR updated their developmental delay projection to 32,900 by 30 June 2023 – which is half of the 67,600 children with developmental delay who were in the scheme by that date.[2775]

In addition to persistently higher than expected entries into early intervention, exit rates from early intervention have also been lower than expected. This suggests that capacity building has not been entirely effective in reducing future support needs.

Here we use developmental delay exit rates data as an indicator of how early intervention participant exit rates have evolved. Figure 179 shows a comparison between expected exit rates from the 2020-21 AFSR and actual exit rates from the 2021-22 AFSR.[2776] The Figure contains two

charts, each showing the actual and expected exit rate for each age group from 1 to 6, for those with a higher level of assessed functional capacity (Delay 1) and those with a lower level of assessed functional capacity (Delay 2). As can be seen from Figure 179, actual exit rates were far below anticipated exit rates for both delay cohorts.

Figure 179: Actual and projected exit rates for developmental delay 1 (top) and developmental delay 2 (bottom) for 2020-21[2777]
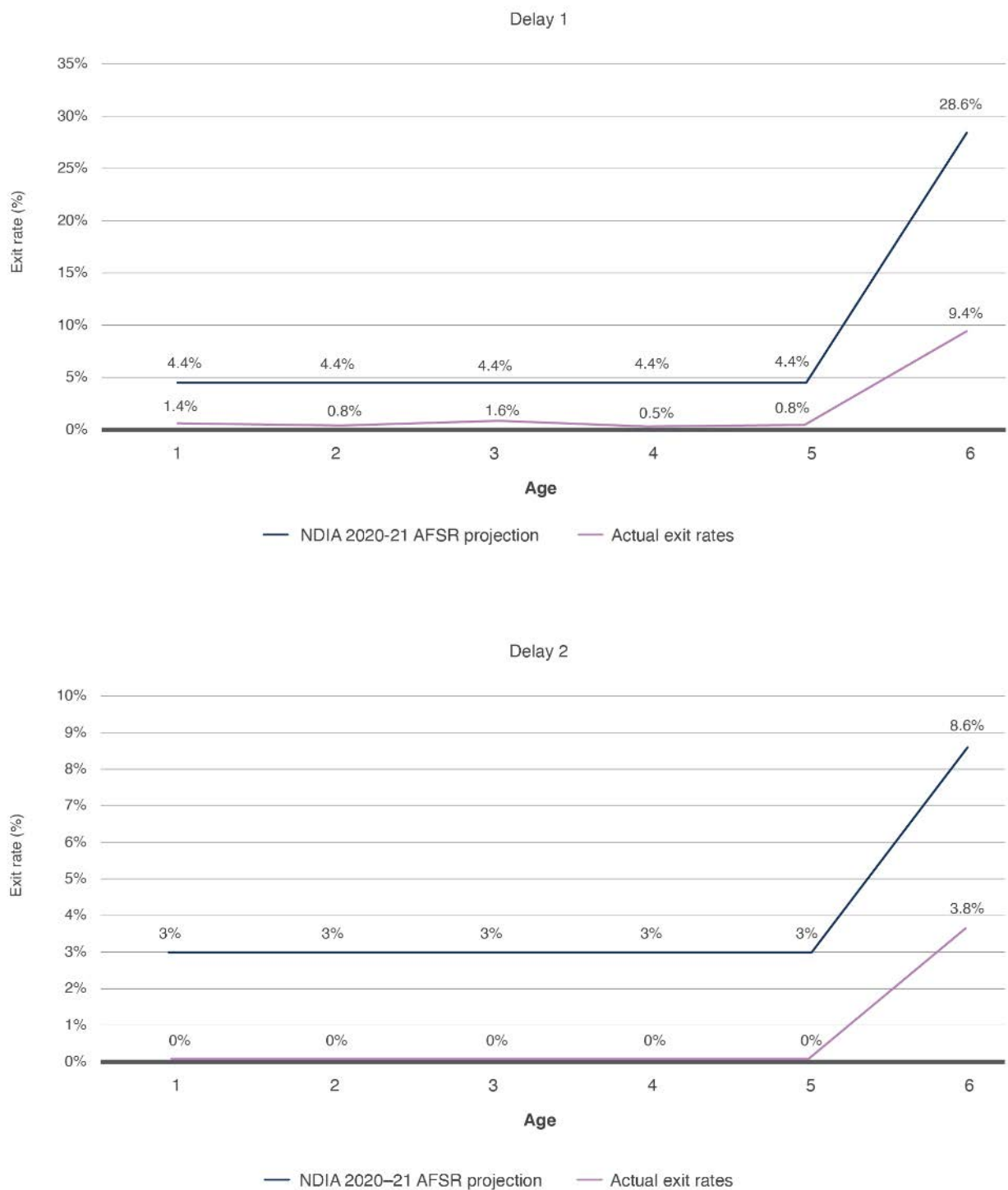
Instead of exiting, the majority of children with developmental delay remain in the NDIS by entering the scheme via a disability diagnosis under section 24 of the NDIS Act. For example, out of a sample of children with developmental delay who entered the scheme before December 2022, for those who were aged 7 or over by December 2022, 74 per cent remained on the scheme mostly through a section 24 diagnosis of autism or intellectual disability.[2778] As a result, the long-term cost of children with developmental delay is increasing.

A primary cause of these trends is that early intervention has simply not been administered as intended. Evidence of poor operationalisation of early intervention was identified by the Productivity Commission in its 2017 report, which concluded high entry rates were largely due to the process of how children entered the NDIS, rather than the eligibility criteria.[2779]

4.5. Ageing participants in the scheme

Australia's ageing population has implications for most government service areas, and the NDIS is no exception. The *Intergenerational Report 2023* projects that increasing life expectancy and declining fertility rates will contribute towards population ageing in future years.[2780] Nearly one-fifth of Australians were aged 65 and over in 2022-23 (17.4 per cent or 4.6 million). This cohort is expected to grow to nearly a quarter of the population by 2062-63 (23.2 per cent or 9.4 million).[2781]

As people age, they are more likely to acquire a disability, or an additional disability. In 2018, almost half of all people aged 65 and over had a disability (49.6 per cent), which represented 1.9 million people, or 44.5 per cent of all people with a disability.[2782] The proportion is much lower for people with a disability aged under 65 at 11.6 per cent.

When the Productivity Commission first estimated the NDIS's future cost in 2011 they did not include participants aged 65 and over. This is because the Productivity Commission assumed there would be no net increase in costs to the Australian Government with respect to this cohort relative to the aged care system.[2783] The Productivity Commission also proposed that participants should have the choice of either remaining in the NDIS or transitioning to the aged care system when they reached qualifying age for the Age Pension.[2784]

In hindsight, omitting people aged 65 and over from initial cost estimates of the NDIS contributed to a significant underestimate of future costs in the scheme due to actual support costs for this cohort turning out to be higher in the NDIS than in the aged care system.

In 2017 the Productivity Commission acknowledged the 2011 Productivity Commission forecast of no net increase due to costs for over 65 being higher after accounting for growth and inflation had created a shortfall of $1.09 billion.[2785] The Productivity Commission revised its estimate of costs for participants over 65 but even this revision has turned out to be less than the actual cost difference between the NDIS and aged care.

The number of participants aged 65 and over as at 30 June 2017 was 1,300, or 1.5 per cent of the scheme.[2786] By 30 June 2023, the number grew markedly to 27,500 participants (4.5 per cent).[2787]

NDIA projections using data up until June 2023 estimate this to reach 75,300 by 30 June 2032 (7.4 per cent).[2788]

Figure 180 shows that spending has also increased for these participants, particularly as funding packages are higher for older participants and continue to increase. In 2017-18, 2.2 per cent of total costs were spent on participants aged 65 and over, but this increased to 7.6 per cent in 2022-23. Based on the NDIA 2021-22 AFSR projections, costs related to those aged 65 and over are projected to reach 12.9 per cent ($11.4 billion) of total scheme costs in 2031-32.[2789]

Figure 180: Historic and projected payments of participants aged 65 and over for years ending 30 June[2790]
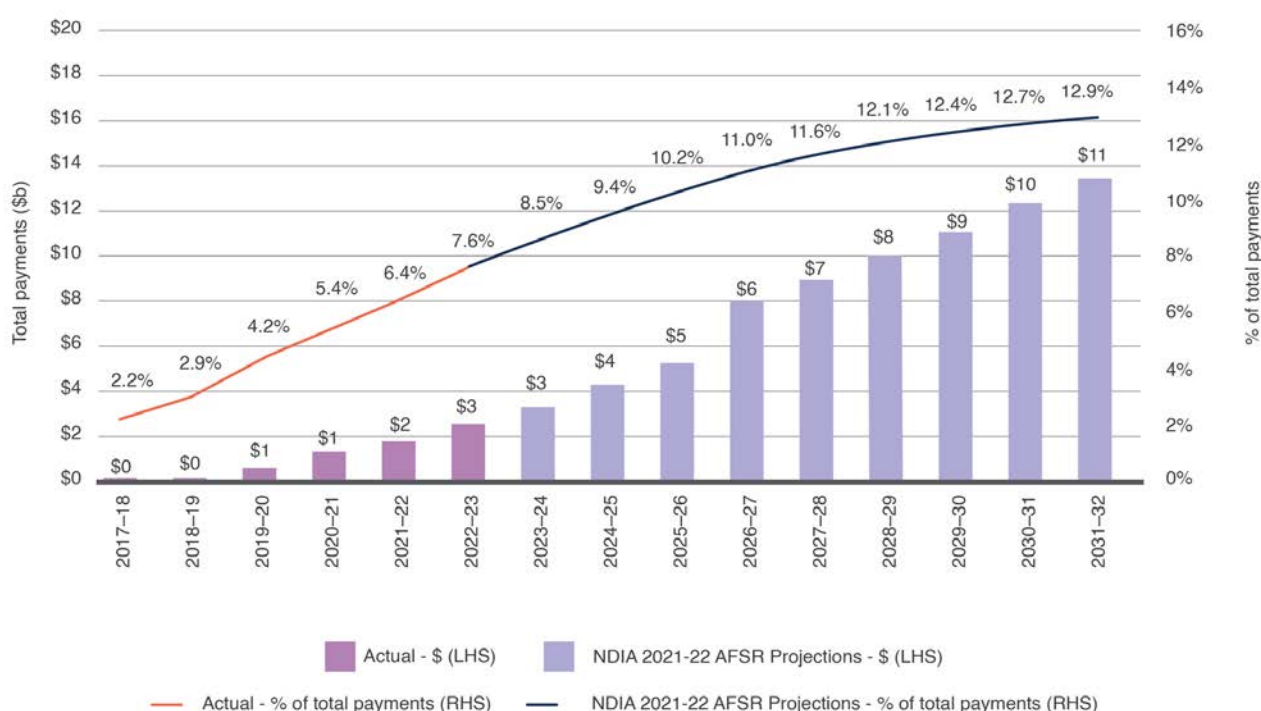
Differences in policy design and operation have created inequities between the NDIS and the aged care system. While people who acquire a disability over the age of 65 are not eligible for the NDIS, participants already on the scheme before they reach 65 are able to remain. As NDIS supports are usually more generous than the aged care supports, there is little incentive for NDIS participants to transition to the aged care system, when this may be more appropriate to their needs.

The Review explores these issues further in Chapter 1, where we consider the issues at the interface between the NDIS and aged care system, and provide options to improve support efficiency, outcomes, and scheme sustainability. The current differences in supports for those who acquire a disability before the age of 65 and those who acquire their disability when they are 65 or older, has been exacerbated by governments not fully implementing the National Injury Insurance Scheme (NIIS). This would have provided NDIS-like benefits to all people who are catastrophically injured when aged over 65. Today, only those injured in motor vehicle and work place accidents can access this no-fault insurance. Further details of the NIIS are in Chapter 1.

4.6.   Supported Independent Living costs are growing

Part of achieving an adequate standard of living for people with disability is ensuring access to suitable housing. In addition to greater funding, one of the central premises of the NDIS is to provide individual funding plans to meet individual needs.[2791] Given the diversity of housing needs and circumstances, the NDIS presented a significant opportunity to deliver better, more effective supports beyond what was possible in the predominately block-funded and rationed systems that existed before.

This has led to a range of housing and living supports being provided by the NDIS. This includes funding for home modifications; home-related assistive technology; Specialist Disability Accommodation (SDA) if more purpose-built accommodation is required; Individualised Living Options (ILO) for participants who do not require 24/7 living supports; and Supported Independent Living (SIL) supports for those with high support needs, and primarily in shared living arrangements.

Costs associated with housing and living supports are among the highest in the NDIS. Costs related to SIL participants provide a useful indicator of the costs of housing and living supports in the NDIS more broadly. As at30 June 2023, there were 31,509 SIL participants who in the 2022-23 financial year averaged $298,300 in payments per participant for assistance with daily life supports, and $387,800 in payments for all supports.[2792]

Up until 2021-22, the number of SIL participants has been lower than earlier scheme projections. The 2018-19 AFSR projected the number of SIL participants to be 35,426 in June 2023.[2793] By the 2021-22 AFSR, the projected number for June 2023 had decreased to 28,311.[2794]

Across 2022-23 the number of additional SIL participants was 4,559 – or 3,198 above the number expected by the 2021-22 AFSR.[2795] While this is a small number relative to the size of the scheme, it has a disproportionate effect on total payments given the high spend of SIL participants. For example, if 3,200 additional participants spend $150,000 more per year, this equates to nearly $500 million per year, or $5 billion across the next decade.[2796]

This recent break from previous SIL projections coincides with a gradual shift in who is receiving housing and living supports. Figure 181 shows the breakdown of participants who received their first SIL plan for each year to 30 June by entry type. As the NDIS rolled out across 2013 to 2022, high needs participants were prioritised, transitioning in from Australian Government, state or territory disability support programs that were operating prior to the NDIS. Consequently, until recently a large majority of new SIL entrants were from former state or territory programs – including above 90 per cent for the years before 2020, 71 per cent in 2019-20, and 56 per cent in 2020-21.

Figure 181: Entry origin of SIL participants for years ending 30 June[2797]
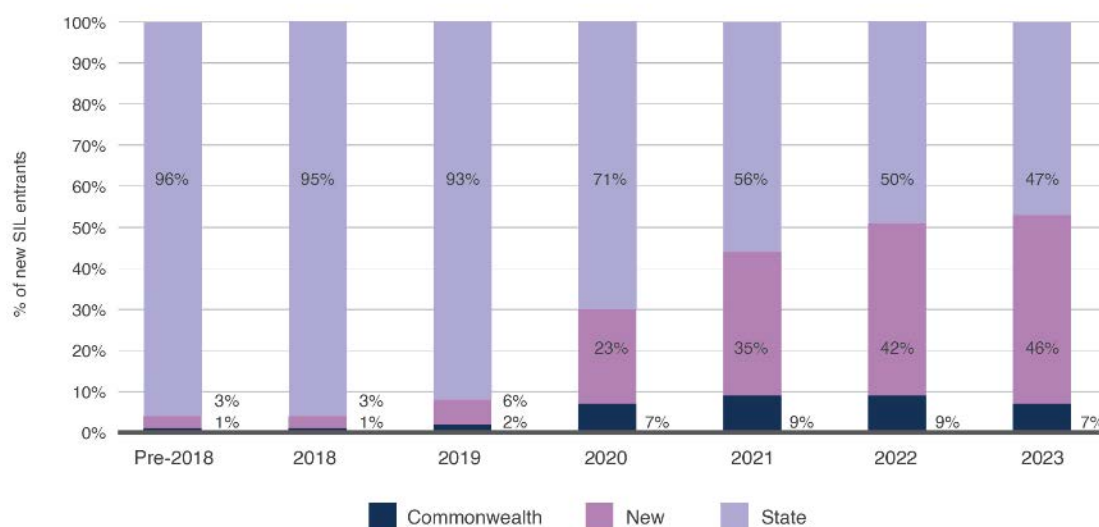
*Figures don't add up to 100% due to rounding

However, ten years into the NDIS, SIL is now supporting a higher proportion of new participants on entry each year. As Figure 181 shows, the proportion of participants receiving their first SIL plan who are new to any disability support system is increasing, from 6 per cent for 2018-19 to 46 per cent for 2022-23.

While the NDIS was always intended to meet needs that were potentially unmet in previous systems, the transition to SIL of participants who did not previously receive support from governments is occurring faster than might have been expected. This is because it is generally recognised that those with the highest needs, before the NDIS commenced, were receiving some level of support from either Commonwealth, states or territories, but there were extreme shortages and long waiting lists for housing and SIL.

In the 2022-23 financial year, total payments by SIL participants on all supports was around $12 billion, or 33 per cent of total NDIS expenditure. [2798] This includes payments by SIL participants for all supports, and not only the payments for SIL supports (e.g. assistance with daily living). Figure 182 shows the total payments by SIL participants over time, based on NDIA 2021-22 AFSR projections. SIL costs are expected to remain around 30 per cent of total scheme costs, rising to $25 billion by 2031-32.

Figure 182: Historic and projected payments of SIL participants for years ending 30 June[2799]
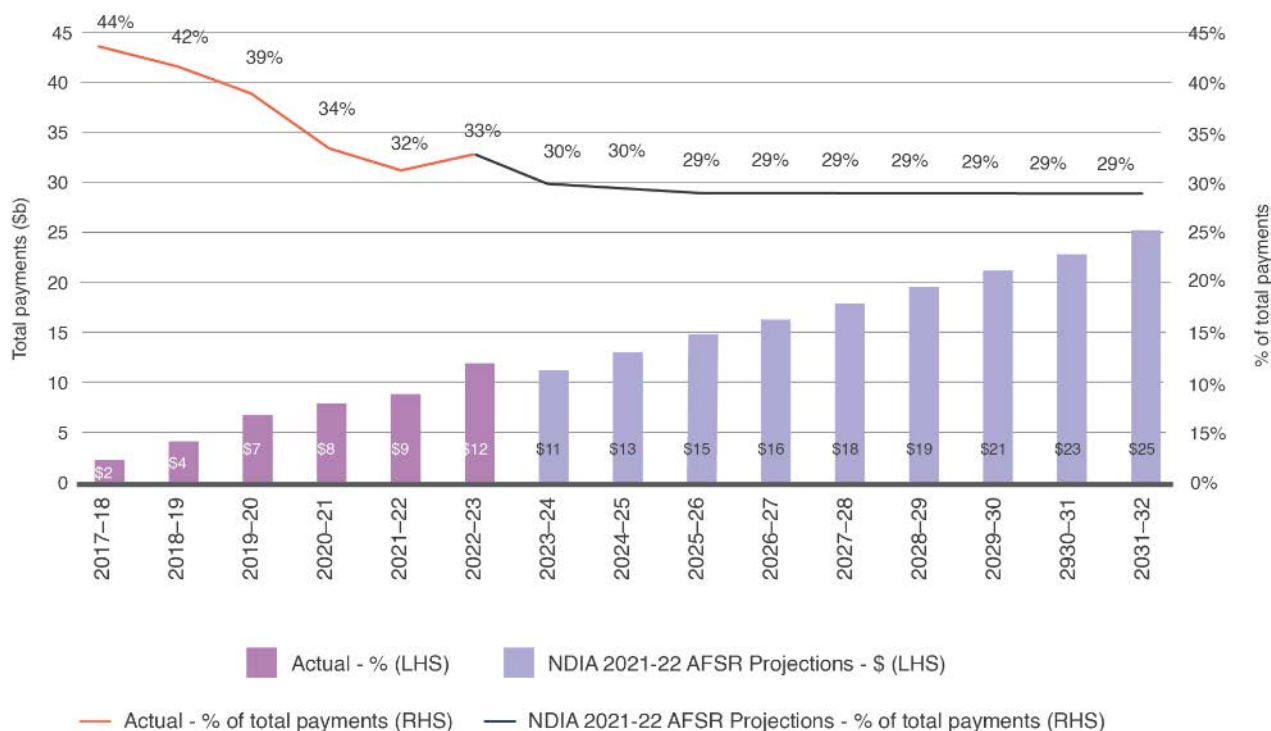
The overall sustainability of the NDIS will be highly sensitive to what direction housing and living supports take. Current issues and recommended reform options are discussed further in Chapter 3.

4.7. Growth in plan size has been higher than expected

Lack of clarity on reasonable and necessary

One of the core criticisms of the NDIS – and one which we have heard continually – is the lack of a clear definition for what constitutes reasonable and necessary supports.

The lack of clarity around reasonable and necessary supports is a key contributor to participant and family member frustration with planning and administrative review processes and generates sustainability challenges for the scheme and governments.

In addition, the NDIA has never had the resources to invest in best practice assessment and planning, even though this is the foundation for an equitable and sustainable scheme. Instead, the NDIS planning process is time-limited, inconsistent, rigid and can fail to adequately reflect a participant's support needs. This has led to ineffective and unfair allocation of funding, which has then fuelled s100 reviews and AAT appeals by those with the time and resources to go through this exhausting and stressful process. This in turn has created further challenges for the NDIA in seeking to make the scheme equitable and sustainable.

Average spending per participant

The growth in average payments per participant is another factor to consider when assessing growth in total scheme costs. Like participant growth, average payments have been higher than expected, and contribute to sustainability pressures facing the scheme.

Over the last four years, average payments per participant increased by 6.0 per cent per annum (Figure 183). This rate of growth reflects increasing prices over time and increasing support needs, including related to ageing.

Figure 183: Average and median payments for participants over time for years ending 30 June[2800]
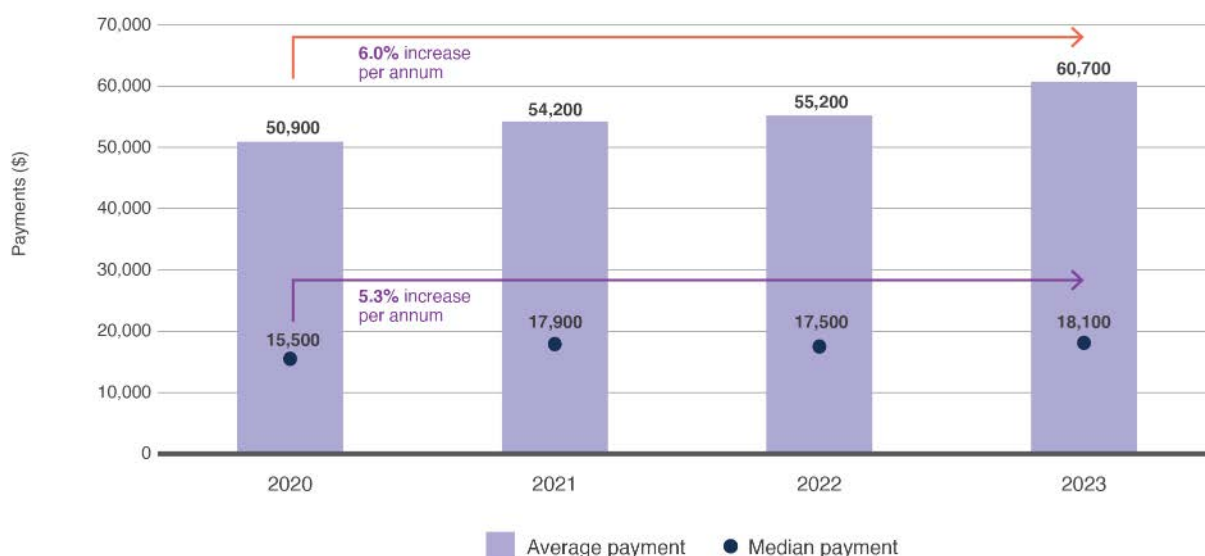
Growth in the average and median payments calculated each year does not reflect how much more individual participants are spending each year. This is due to spending of new participants who enter the scheme each financial year. In other words, changes in average and median payments can be affected by compositional effects from year to year. This is what is happening with the NDIS. For instance, on average, more people are entering the scheme with relatively lower support needs (plan size and utilisation) each year and this reduces the average and median payments for participants. As such, average and median costs per participant are not a good indicator of inflation 'within the scheme' from year-to-year.

From June 2020 to June 2023, more than 200,000 participants joined the NDIS.[2801] The majority of these participants were young children, with plan values often around $25,000 or less.[2802] The payments associated with these plans are less as participants do not spend all their plan budget. Consequently, the 6 per cent increase shown in Figure 183 actually reflects two trends.

- First, new participants entering with typically lower payments brings down the average payments – the effect of this is evident as the median payment declines from $17,900 in 2020-21 to $17,500 in 2021-22, even as the average payment increases, indicating there are more low spend participants entering the scheme which has caused the median to fall.
- Second, spending by existing participants was rising faster than 6 per cent.

Participant spending rises over time in the scheme

When the 2017 Productivity Commission report identified key emerging cost pressures, it cited increased spending but noted this was only in relation to the change from the first to second plan, and second to third plan.[2803] It referred to these plans specifically because at the time, four years into the rollout of the NDIS, this was the only data they had available to them.

The same plan-on-plan data can now be revisited with the benefit of more time, and more participants in the scheme.

Figure 184: Average annualised spending for participants over time[2804]
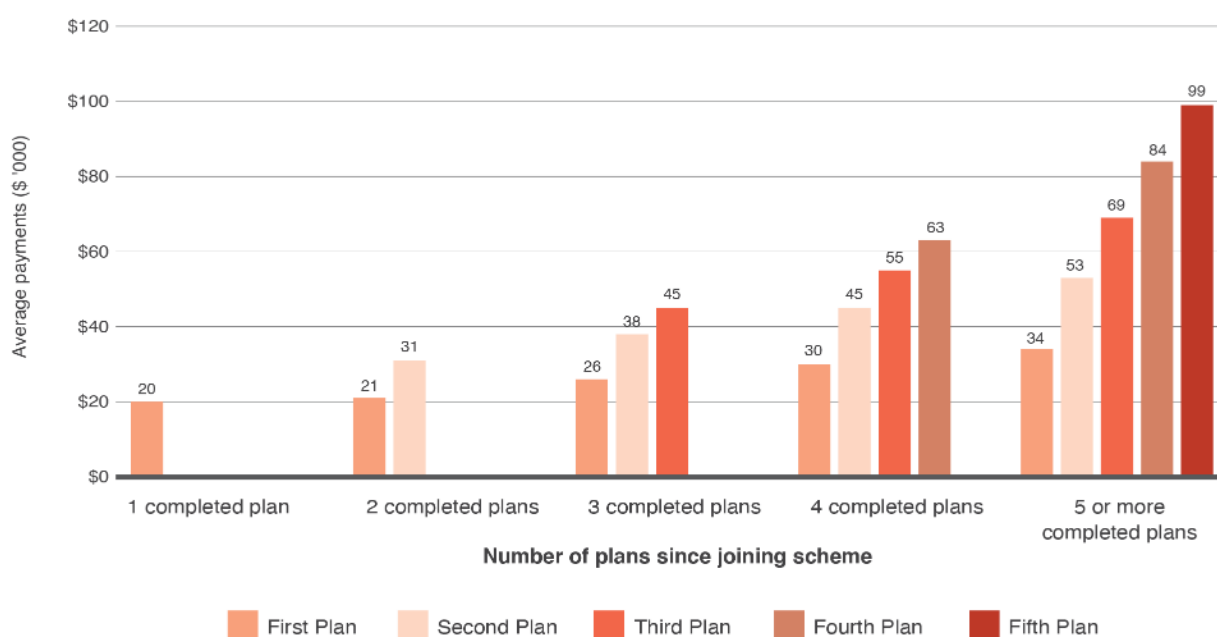
Figure 184 shows the average annualised payments for participants by each completed plan, separated into how many completed plans a participant has had since joining the scheme. While the 2017 Productivity Commission only had a limited number of participants who had completed three or more plans at the time of its review, we can now focus on a larger number of participants who have completed five or more plans.

For participants who have completed five or more plans, the rate of increase across the first five plans is significant. There is a three-fold increase from $33,600 in average payments at the first plan, to $99,300 by the fifth plan. The rate of increase is highest amongst the earliest plans, where average payments increase by more than 50 per cent from the first to the second plan, before declining with subsequent completed plans. Participants who have spent less time on the scheme generally have a lower rate of increase, but still show a similar pattern of increasing spending over time.

A partial cause of these significant increases is the common experience of participants where it takes some time before they start fully spending their plan budgets. This can take time and

numerous plans as participants learn to navigate the NDIS, find support options and settle on regular providers. Consequently, spending in the first plan, or first few plans, could be considered artificially low while participants become acquainted with the NDIS.

How much of their budget a participant uses increases with each plan

This trend is evident in how participant utilisation changes over time, shown in Figure 185. The proportion of a plan budget which a participant uses is referred to as the utilisation rate. It is clear that participants on their first plan only use, on average, half their plan. This rate quickly increases by the second plan, and continues to increase across subsequent plans, nearing a utilisation rate of around 80 per cent by the time a participant has been in the scheme for five completed plans.

Figure 185: Utilisation rate for participants over time[2805]
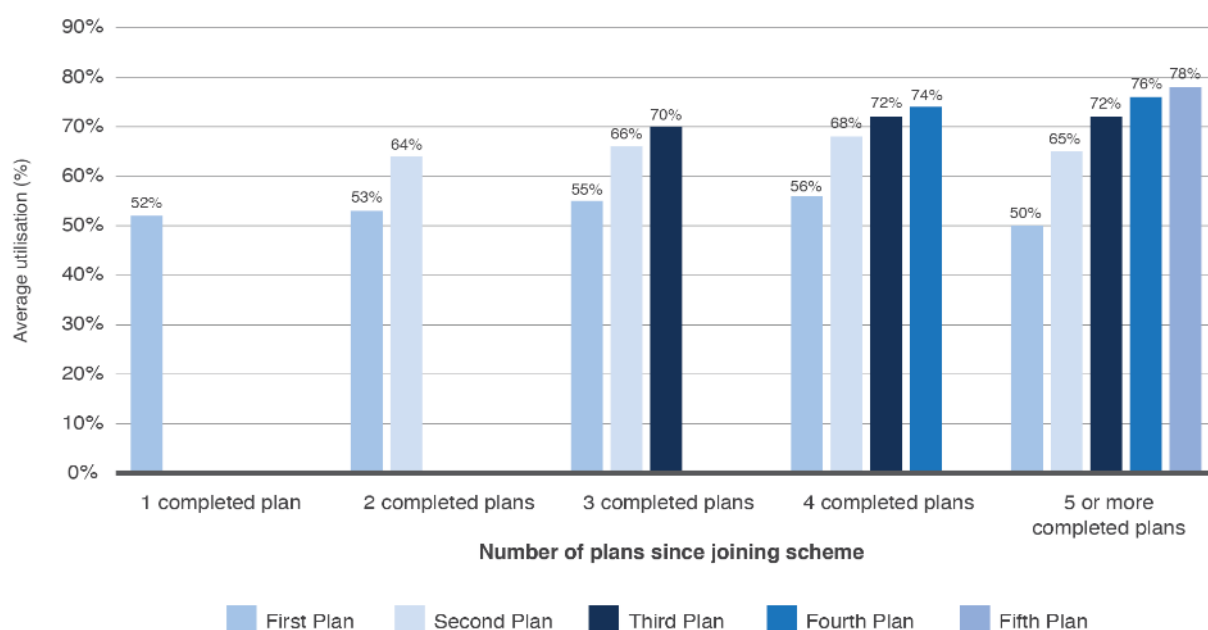
Separate to utilisation, the other driver of how participant payments change over time is how their plan or budget size changes over time. In fact, given the issue of low utilisation as participants join the scheme, the rate of increase in plan budgets is likely a better indicator of how the planning process contributes to growth in NDIS costs.

Figure 186 shows the average plan budgets for participants across their planning cycles, separated into how many plans they have had since joining the scheme. It shows a more modest, but still similarly high, growth rate as the earlier Figure 183 on average payments. For participants with six plans, the average annualised plan budget has increased from $67,100 in the first plan to $141,900 by the sixth plan. The rate of increase from one plan to the next is declining over time. However, even from the fifth to sixth plan the rate of increase is still above 11 per cent.

Figure 186: Annualised plan budgets for participants over time[2806]
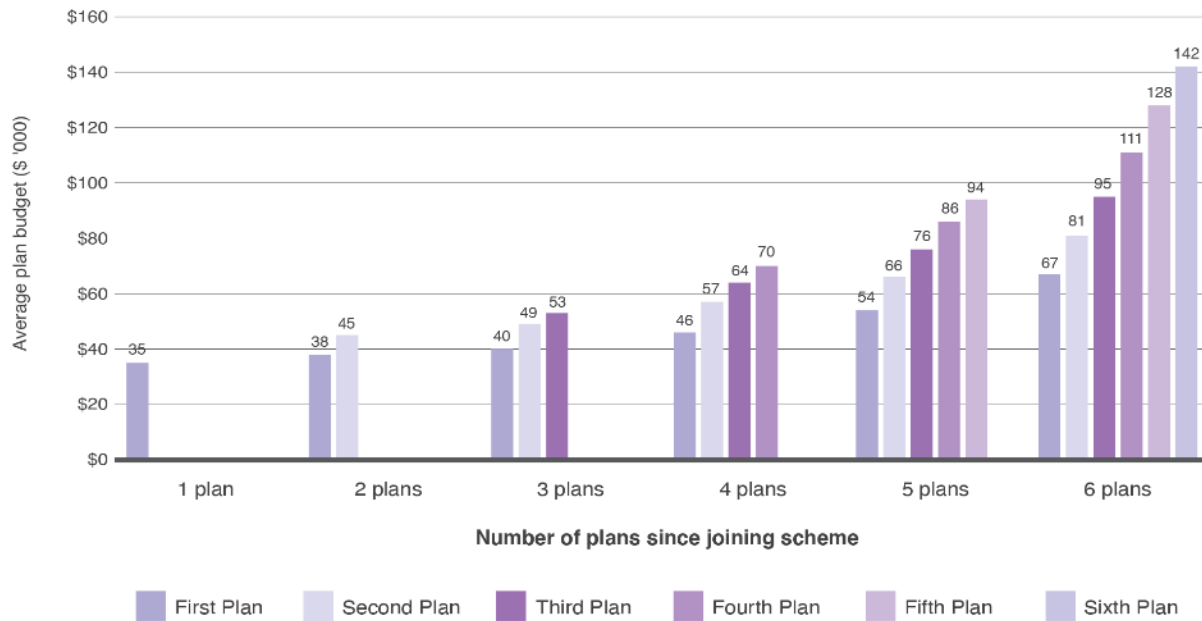
Figure 187 shows the average annualised plan inflation rate each quarter since June 2019. Excluding a COVID-affected period in 2021, annualised plan increase has rarely dropped below 12 per cent. It also highlights plan increase regularly reaching 20 per cent in 2019-20, then declined to an average of 6 per cent during 2020-21, before rebounding to 15 per cent in 2022-23.

Figure 187: Annualised percentage change in plan budgets for active participants[2807]
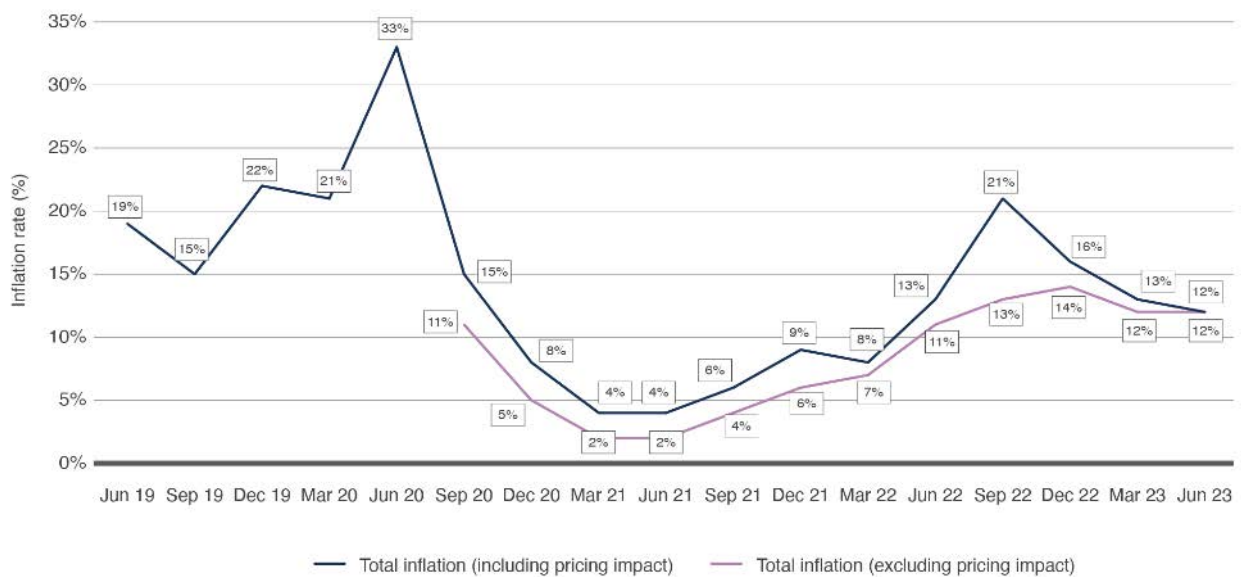
The majority of these changes are due to increasing quantity of supports, rather than the impact of price changes

To understand underlying scheme dynamics, the total increase rate with the impact of price changes should be removed. This is described as the 'real' growth rate and is shown as a series from Q1 of 2020-21 onward. It is usually two to three percentage points lower than the total increase rate. The exception is following a significant update in prices in July 2022. Since Q1 of 2020-21 the real growth rate has ranged from a low of 2 per cent to a high of 14 per cent.

High plan increase is a feature across the NDIS, and analysis undertaken by the NDIA and Melbourne Disability Institute has not found relationships between plan increase and participant characteristics including primary disability, SIL or non-SIL plans, age, gender, socioeconomic status, cultural background, or geography.[2808] High plan increase is apparent with longer-term scheme participants who have had multiple plans and underlines the persistent nature of inflation within the scheme. It was expected that participants who have had multiple plans and reviews would receive consistent plan budgets as their disability is better understood, or support needs potentially stabilised. However, as shown in Figure 186, this has not occurred.

Persistent plan increases reflect underlying structural issues with the scheme

When the 2017 Productivity Commission report named high plan increase as an emerging sustainability challenge its analysis was based on data from 2015-16, when plan increase was between 10 and 12 per cent per annum.[2809] Against this benchmark, the issue of high plan increase has not been adequately addressed to date. In fact, excluding for the COVID-19 affected period the issue of plan increase has become an even greater sustainability pressure.

High, widespread and persistent plan increase over the first ten years of the NDIS likely reflects underlying structural issues with the scheme. This needs to be understood and addressed if the NDIS is to meet the 8 per cent sustainability target set by National Cabinet.

The two areas of reform most relevant to addressing plan increase are the participant experience and markets.

- A poor planning process not focused on participant needs and without a clear definition of reasonable and necessary supports, will affect plan adequacy. This is discussed in Chapter 2.
- Markets that do not work effectively in delivering supports to participants, leading to a range of issues that are likely to be contributing to high plan increases. These issues are discussed in Chapter 4.

4.8.   The NDIS is still maturing in relation to hard to reach groups

Despite the NDIS supporting more than 610,000 participants as at 30 June 2023, the scheme does not yet appear to have reached full maturity. Some population groups and communities remain under-served, and there is unmet and a likelihood of additional demand in some locations.

The Review's internal analysis suggest there may be additional demand among people with a primary psychosocial disability, people with a demand for SIL, and people identifying as First

Nations and culturally and linguistically diverse communities. Given these areas are included in the package of reforms the Review is recommending, we are comfortable that these risks can be managed within the growth target set by National Cabinet.

High rates of people reporting a psychosocial disability with significant functional impairment outside of the NDIS, combined with limited foundational supports, could represent a significant source of future cost pressure for the scheme. As a 30 June 2023, 62,000 or 10 per cent of participants have a primary disability of psychosocial disability. However, the Productivity Commission reported that approximately 800,000 Australians have a severe mental illness, with 300,000 having a persistently severe mental illness, and 500,000 an episodically severe illness.[2810] The number of Australians experiencing a persistently severe mental illness is substantially higher than the number of people in the NDIS with a primary disability of psychosocial disability.

As discussed in section 4.6, growth in SIL participants has been unexpectedly high recently, suggesting this is an emerging area of demand growth for the NDIS. We analysed 2021 Census data, and found there were approximately 17,000 people aged under 50 who needed assistance with core activities, did not currently receive SIL support, and lived with a household member that provided unpaid care who is aged over 65. In the absence of the older household member who provides care, these people may require additional SIL assistance in the future. As of 1 January 2023, 44 per cent of these people were not on the NDIS, while the remainder had a NDIS plan but were not receiving SIL support.[2811]

There is also some evidence of unmet demand among First Nations people with a disability. In 2020, the First Peoples Disability Network estimated there were between 57,000 and 61,000 First Nations people with severe and profound disability based on estimates utilising 2015 SDAC, 2014-15 National Aboriginal and Torres Strait Islander Social Survey (NATSSIS) and 2016 Census data. This estimate is higher than the 46,694 participants who identify as First Nations people as at 30 June 2023. While noting there may be reporting discrepancies regarding self-identification, we recommend further research in this important area. Based on 2021 Census data, we found over 30,000 First Nations people aged under 65 who responded that they needed assistance with core activities, but did not have a NDIS plan as of December 2022.

Australians from culturally and linguistically diverse backgrounds may also be under-represented in the scheme. As at 30 June 2023, 9.1 per cent of participants identified as having a culturally and linguistically diverse background. In comparison, various definitions of Australians with a culturally and linguistically diverse background suggest a population average of between 20 and 30 per cent. A comparison using 2021 Census and NDIS participant data with an aligned definition of culturally and linguistic diversity, and making appropriate adjustments for differences in residence eligibility and incidence of disability, suggests there could be a significant degree of under representation of culturally and linguistically diverse people in the NDIS.

We recommend further research in these areas, as these sources of additional demand may indicate the scheme has not fully matured. This could result in higher growth in participant numbers and spending in the short-to-medium term until the support needs of these cohorts are met within or outside of the NDIS. Further discussion is contained at Action 20.1.

5. Challenges in assessing the benefits of the NDIS

Assessing the benefits and outcomes of the NDIS is an important input into understanding how governments' considerable additional investments are delivering better outcomes for participants and to ensuring a more sustainable scheme in the future.

However, there are a number of challenges in assessing the benefits of the NDIS. As discussed in Chapter 6, some of these challenges relate to the limitations of the current NDIS Outcomes Framework, and a lack of objective quantitative measures. We make recommendations for investment in improved data capability in Chapter 6.

There are also a range of other complexities in measuring scheme benefits, including:

- That benefits may take time to materialise once a participant joins the scheme, including from the investment in early intervention and capacity building, and this is generally the case with a majority of new participants who have accessed the scheme since 2018-19
- A lack of comparable data on previous disability legacy service systems and other comparable schemes
- An inability to currently undertake data linkages to assess the benefits from improved outcomes related to other service systems (e.g hospitals, child protection and justice)
- An inability to assess participant benefits from improved access and engagement with school or post school education
- A lack of data to accurately assess scheme benefits related to the replacement of private and charitable spending on disability supports with government funded disability support, and the substitution of unpaid care for paid care.
- How mainstream service systems are impacted from increased participation in the NDIS.

Notwithstanding these limitations, we commissioned Taylor Fry to estimate the net benefits of the NDIS compared to legacy disability service systems. Taylor Fry used various techniques to estimate the NDIS's net economic and wellbeing benefits in monetary terms, and compared these to the net additional costs of the NDIS relative to a projected counterfactual scenario where the legacy disability systems were assumed to continue. Stated differently, 'net' benefits and costs refer to measurable increases in benefits and costs over and above those that were likely to have been realised under legacy systems if they had continued without the NDIS.

While Taylor Fry were able to estimate substantial net economic benefits from the NDIS compared to legacy disability systems, particularly relating to enhanced life satisfaction for participants and carers, their analysis was subject to a range of data limitations and measurement difficulties (as outlined above) and is likely to be a significant underestimation of scheme benefits. There are also methodological inconsistencies in the Taylor Fry modelling that conflict with the Productivity Commission's approach.

On this basis we do not consider this analysis a reliable estimate of scheme net benefits. However, it does again highlight the need for more and better quality data to reliably evaluate scheme

outcomes and benefits over time, and the challenges involved in quantifying the benefits of such a large and life-changing national scheme.

As discussed earlier, the main benefit that the NDIS provides to all Australians is comprehensive insurance with respect to the additional costs associated with disability. As noted above, the NDIS is a response to significant insurance market failure and this is expected to be associated with very large efficiency and welfare gains. Measuring the consequent efficiency and welfare gains will be an important area for future research as part of measuring the benefits of the NDIS and building on the initial work of Taylor Fry.

To place the insurance value of the scheme in perspective, Vu et al. (2020) found that people with a disability in Australia would need household disposable income 50 per cent higher in the short run compared to those without a disability to achieve the equivalent standard of living, and over 100 per cent higher for those with significant disabilities.[2812]

Further, Chandra and Samwick (2005) estimated that in the United States the average person would be willing to give up five per cent of lifetime expected consumption to comprehensively insure for acquired disability, and potentially a further four per cent to insure for a significant acquired disability. This is in addition to disability-related social security benefits. To place this result in Australian context, in the 2022-23 financial year five per cent of household consumption amounts to around $63 billion in current price terms, and nine per cent amounts to around $114 billion.[2813]

While no similar analysis yet exists for Australia, and noting the significant conceptual challenges and uncertainty involved, we believe that an evaluation of the insurance benefits of the NDIS would most likely result in significant additional benefits not accounted for in the Taylor Fry analysis.

In undertaking this work we identified a range of data gaps and conceptual challenges that need to be addressed before a more comprehensive economic and social evaluation of the NDIS is possible. We have made several recommendations to help address gaps in data availability, linkage and use, and research and evaluation activities, to help address these data and knowledge gaps (see Chapter 6). We believe that addressing these evidence gaps will be critical to help improve NDIS sustainability and outcomes in the longer-term.

One potentially interesting area which we did not have an opportunity to consider, because it is outside our Terms of Reference, is the insurances that are part of superannuation. When compulsory superannuation was introduced, and it was decided to include total and permanent disability (TPD) insurance, the NDIS did not exist. It of course only provides insurance for those who are working and arguably the benefits from this insurance are more akin to income protection than disability insurance. However, an examination of the potential synergies between the NDIS and superannuation-based TPD insurance should be considered by governments at a future date, as they consider the broader issue of the adequacy and efficiency of current insurance arrangements.

6. Setting the scene for reform

6.1. Our analysis shows more work is required to improve the operation of the scheme and how we measure it

In 2011 the Productivity Commission found that legacy disability support systems, and public and private disability, health and accident insurance schemes were likely to be significantly underproviding disability insurance to all Australians. The introduction of the NDIS means that we are now much closer to providing adequate disability insurance to the Australian community, particularly with respect to the risks of significant disability. This is a key reason why the NDIS is important to all Australians and a critical reason to strengthen and improve the NDIS in the future.

Another important insurance dimension of the NDIS is that it provides a mechanism to allocate risks efficiently to those who have the greatest capacity to bear them, and to ensure that spending on disability supports is cost-effective, and potential future liabilities are being efficiently managed. With the NDIS now providing more comprehensive disability insurance, we have a much better perspective on disability prevalence and support needs than previously. This will enable these support needs to be managed in a more efficient and equitable manner in the future, both within the NDIS and the broader disability and foundational support systems.

The insurance principles underpinning the scheme also support a conceptualisation of NDIS sustainability that goes beyond costs alone and considers benefits and risks. Therefore, in seeking to address NDIS sustainability, our reform priorities seek to manage the risks of rising scheme costs fairly and efficiently, to maximise net benefits to participants, family members and the broader community whilst delivering disability insurance and supports in the most cost-effective manner.

Alongside the implicit insurance value of the scheme for all Australians, we have found evidence that the scheme is delivering improved wellbeing and financial security for people with disability and their family members. We have also found some evidence of improved incomes and labour force participation as well as reduced spending in other foundational and disability support systems.

While this is encouraging, it is also clear that additional effort is required to improve the participant experience and ensure that more evidence-informed approaches are funded to support the capability of participants, their family members and supporters to lead lives they value.

Considerations of fairness towards other groups reliant on government support also demand that ongoing efforts are made to ensure that the scheme is being delivered in the most cost-effective manner.

This requires the capacity to more clearly link benefits to supports and investment and evaluate the likelihood of net benefits. There should be a more rigorous evidence-based assessment of which supports are suitable for government subsidy or support. There should also be careful consideration of which supports are best provided within the NDIS and which are better provided via support systems outside of the NDIS.

This concern for cost effectiveness also demands we carefully examine cost pressures in the NDIS as identified above, and areas where cost inflation remains unexpectedly high. In this regard, we have developed a range of targeted reform proposals for participants, foundational supports, home and living, markets and governance that are intended to improve NDIS sustainability.

6.2.   Means testing and co-payments won't address scheme sustainability

As an alternative to our targeted approach to addressing sustainability, some have suggested means-testing eligibility to the NDIS or co-payments for NDIS supports may be the answer to the sustainability of the scheme. We don't believe this to be the case as a matter of good public finance principles and public policy. On practical grounds, most participants have very low incomes and households with participants also tend to be relatively disadvantage compared to those without participants.

As a matter of principle, the NDIS provides universal insurance against the risk of additional costs associated with disability. Prior to the NDIS there were incomplete or missing markets for disability insurance and these risks could not be fairly or efficiently pooled and shared across the community. There were insufficient incentives to manage risks and associated costs and risks were not allocated to those best able to manage them. Comprehensively addressing the missing or incomplete markets problem requires universal insurance.

The NDIS is also intended to support the independence social and economic participation of people with disability. The NDIS Act recognises that people with disability should be supported to participate in and contribute to social and economic life. Reasonable and necessary supports are provided through the NDIS to assist people with disability to meet their goals and maximise their independence. Through means testing or co-payment arrangements the NDIS would instead be disincentivising economic participation for NDIS participants.

Analysis of ABS data from 2019 shows only 23.4 per cent of participants were employed, less than one third the rate of the non-participant population (71.7 per cent).[2814] Of those who are employed, the 2020 NDIS Employment Outcomes Report indicated that only 48 per cent of participants aged 15 and over with a paid job at baseline were employed in open employment at full award wages.[2815] Introducing means-testing or co-payments could further disincentivise employment for participants.

Analysis we have undertaken also suggests that NDIS spending is already reasonably well targeted towards low-income individuals and households. Analysis of linked social security and NDIS participant data showed that almost 78 per cent of participants over the age of 16 are on some form of government support payment, including over 70 per cent on the Disability Support Pension (DSP).[2816]

Given most participants also qualify for means-tested social security payments, it is unlikely the introduction of means-testing or co-payments would significantly reduce scheme costs. It would also add to the complexity of the scheme, hindering participant experiences and increasing the administrative burden of running the scheme.

We believe the best way to provide a sustainable NDIS is to ensure that people with disability and their families maintain access to disability supports that are reasonable and necessary and are likely to be beneficial and cost effective. The NDIS was designed to provide universal support for all Australians should their lives be significantly affected by disability. We do not support means-testing or co-payments and believe there are far better and fairer options to safeguard scheme sustainability.

7. The blueprint for a more sustainable NDIS

From the beginning of the Review, our belief has been that we should focus on reforms that make sure all people with disability can get the supports they need, when and where they need them. We have kept the three key elements of our Terms of Reference at the forefront of our approach:

- Putting people with disability at the centre of the NDIS.
- Restoring trust, pride and confidence in the NDIS.
- Ensuring the scheme is sustainable and so there for future generations.

Given this approach, a more sustainable scheme will be the outcome of, rather than the sole driver of our reforms.

A more person-centred, fairer NDIS, embedded in a balanced ecosystem of support that is easier to navigate and delivers high quality supports will result in a sustainable scheme.

We know sustainability is about more than just costs, it's also about outcomes. Our reforms are designed to ensure that each dollar spent on the scheme maximises benefits by supporting participants to achieve their goals in the most efficient manner.

Our reforms are also designed to enhance scheme integrity. Providers and workers should not be able to fly under the radar and the NDIA should be able to see where every dollar is spent.

By improving the NDIS, foundational supports and the broader disability support ecosystem around it, it will be possible to get better outcomes for all people with disability in a more efficient and cost-effective way.

All governments are accountable for the sustainability of the disability support ecosystem. It is impossible for the NDIS to be sustainable without a commitment by governments to improve foundational supports outside the NDIS and make mainstream services more accessible and inclusive. This is the most important way to improve scheme sustainability and reduce pressure for NDIS support.

The reformed participant pathway is designed to give an improved experience where people are supported, valued and heard. At the same time, the needs-based approach to budget setting will prioritise evidence-based supports that lead to a more manageable scheme. Our recommendation for service navigators will help participants access NDIS supports, better manage their budget, choose supports that deliver outcomes that matter to them, and reduce costs of plan management.

Improving data quality, availability and linkage will help deliver a more evidence-based scheme that promotes value for money investments. Increasing the focus on measuring outcomes, and linking outcomes to provided supports, should create an environment where participants see better results, innovative practices are incentivised, and scheme sustainability is improved.

Innovative approaches include improved opportunities to share supports, particularly housing and living supports, where this can provide a more cost-effective way of ensuring participants' needs are met, while also providing for more individualised living arrangements.

An enhanced real time payment system can improve the transparency of transactions, deter fraudulent or sharp practices, and reduce wasteful spending.

We also need more workforce planning, training and incentives to make careers in the disability sector more attractive. Without the right workforce, our reforms will not succeed.

We have not designed these reforms to fit pre-determined targets agreed by governments, but rather because they are the right things to do to improve participant experiences and outcomes, while also providing better value for money and helping to secure the success of the NDIS.

While we have found evidence that the NDIS is delivering some of the originally intended benefits for people with disability, their family and supporters, we believe it is clear the scheme could be doing better in many respects. We have discussed how it is currently difficult to link outcomes and benefits to the provision of particular supports or investments in the scheme and it is likely that many of the scheme's benefits are currently unmeasured or poorly measured. A stronger evidence-base is required to underpin many of the therapies, supports and interventions funded by the NDIS and to reduce spending on therapies, interventions and supports where there is limited evidence to suggest that they will be net beneficial, safe and cost-effective.

We have examined the potential impact of our recommendations on scheme projections. If implemented together, we are confident our reforms will secure the future of the scheme and meet National Cabinet's NDIS Financial Sustainability Framework annual growth target in total costs of the NDIS of no more than 8 per cent by 1 July 2026 with further moderation of growth over time.

By the time the reforms mature in 2032-33, we expect cost growth in the scheme itself to have gradually moderated and be within the implied target of $87 billion in 2032-33. However, this will be impossible without significant investment outside of the scheme. First and foremost, investments are needed in foundational supports and in making mainstream services more accessible and inclusive. These will reduce pressure for NDIS support. It will also create a fairer and better system of support for all people with disability.

What will be critical from the perspective of the disability community is that governments commit to fully funding foundation supports over time, through the Foundational Supports Statement of Intent, and that government budgets then include credible expenditure projections. This was the approach adopted by governments when the NDIS was introduced and gave the disability community the confidence in the reform path that was needed then, and now.

Appendices

Appendix A: Acronyms and Glossary

Acronyms

Acronym	Term
AAT	Administrative Appeals Tribunal
ABS	Australian Bureau of Statistics
ABCB	Australian Building Codes Board
ACCO	Aboriginal Community-Controlled Organisation
ACCHO	Aboriginal Community Controlled Health Organisation
ADL	Assistance with Daily Life
ADS	Australia's Disability Strategy
ADS Advisory Council	Australia's Disability Strategy Advisory Council
AFSR	Annual Financial Sustainability Report
ASGS-RA	Australian Statistical Geography Standard – Remote Areas
ALRC	Australian Law Reform Commission
AHURI	Australian Housing and Urban Research Institute
AIHW	Australian Institute of Health and Welfare
API	Application Programming Interfaces
APSC	Australian Public Service Commission
APTOS	Applied Principles and Tables of Support
ARC	Australian Research Centre
ASA	Adult Safeguarding Agencies
AT	Assistive Technology
BSP	Behaviour Support Plan
C-POS	Claims at point of support
CDAH	Community Disability Alliance Hunter
CFFR	Council on Federal Financial Relations
CFP	Coordinated funding proposals
CHIA	Community Housing Industry Association
CHP	Community housing providers

Acronym	Term
CLI	Community Living Initiative
COAG	Council of Australian Governments
COAG Reform Council	Council of Australian Governments Reform Council
CQC	Care Quality Commission
CoS	Commonwealth Continuity of Support Program
CRC	Cooperative Research Centres
CSDA	Commonwealth State Disability Agreement
CSTDA	Commonwealth State Territory Disability Agreement
CTG	Closing the Gap
CVS	Community Visitor Schemes
DAC	Disability Advisory Council
DDA	Disability Discrimination Act 1992
Disability Royal Commission	Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
DOC	Disability Outcomes Council
DREF	Disability Research and Evaluation Fund
DRMC	Disability Reform Ministerial Council
DRO	Disability Representative Organisation
DSOA	Disability Support for Older Australians
DSP	Disability Support Pension
DSS	Department of Social Services
DSW	Disability support worker
ECEI	Early Childhood Early Intervention
FFA	Federation Funding Agreement
FPDN	First Peoples Disability Network
GP	General Practitioner
HACC	Home and Community Care
HSU	Health Services Union
IAC	NDIS Independent Advisory Council

Acronym	Term
ICF	International Classification of Functioning, Disability and Health
IEP	Investment Effectiveness Program
IGA	Intergovernmental Agreement
IGR	Intergenerational Report
IHACPA	Independent Health and Aged Care Pricing Authority
ILC	Information, Linkages and Capacity Building
ILO	Individualised Living Options
JSC	Joint Standing Committee on the National Disability Insurance Scheme
LAC	Local Area Coordinators
LGBTIQA+SB	Lesbian, Gay, Bisexual, Intersex, Queer or Questioning, Sistergirl and Brotherboy
LHDG	Liveable Housing Design Guidelines
MADIP	Multi-Agency Data Integration Project
MBS	Medicare Benefits Schedule
MRFF	Medical Research Future Fund
MSAC	Medical Services Advisory Committee
MMM	Modified Monash Model
MoU	Memorandum of Understanding
MTA	Medium Term Accommodation
NACCHO	National Aboriginal Community Controlled Health Organisation
NCC	National Construction Code
NDA	National Disability Agreement
NDDA	National Disability Data Asset
NDS	National Disability Strategy
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Act	National Disability Insurance Scheme Act 2013
NDIS Commission	NDIS Quality and Safeguards Commission
NDRP	National Disability Research Partnership

Acronym	Term
NDS	National Disability Strategy
NHMRC	National Health and Medical Research Council
NIIS	National Injury Insurance Scheme
OECD	Organisation for Economic Co-operation and Development
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PLIDA	Person Level Integrated Data Asset
PSG	Participant Service Guarantee
QDN	Queenslanders with Disability Network
RIS	Regulation Impact Statement
SAA Trust	Supported Affordable Accommodation Trust
SCHADS	Social, Community, Home Care and Disability Services Award
SDA	Specialist Disability Accommodation
SDAC	Survey of Disability, Ageing and Carers
SIL	Supported Independent Living
SILC	Supported Independent Living Cooperative
SOMIH	State Owned and Managed Indigenous Housing
SRS	Supported Residential Services
STAA	Short Term Accommodation and Assistance
STEI	Short Term Early Intervention
TAP	Targeted Action Plan
TTP	Temporary Transformation Payment
Tune Review	2019 Review of the National Disability Insurance Scheme Act 2013 by David Tune AO PSM
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
URP	Unauthorised Restrictive Practice
WHO	World Health Organisation
WWCC	Working with Children Checks

Acronym	Term
WAiS	Western Australia's Individualised Services
YPINHNA	Young People in Nursing Homes National Alliance

Glossary

Word	Definition
24/7 living supports	Participants who require at least 8-hours of active support and/or supervision with activities of daily living and some level of support for the remaining hours of the day while at home, including overnight (whether active or passive assistance). For some participants, 24/7 support may entail active support for every minute of every day, however, this is only in specified circumstances.
Applied Behaviour Analysis (ABA)	An approach to understanding and changing behaviour.[2817]
Access list	A series of lists designed to automate and streamline access decisions for people with disability to the NDIS.[2818] • List A - a list of conditions that are likely to meet of all elements of the disability requirements under section 24 of the *NDIS Act*. • List B - a list of conditions that are likely to result in permanent impairment in line with sections 24 or 25 of the *NDIS Act*. • List C - a list of programs previously funded by state and territory governments where access was deemed to be equivalent to NDIS access criteria. • List D - a list of conditions where a child under 7 will meet early intervention requirements under section 25 of the *NDIS Act* without further assessment.
Active Support	Describes person-centred practice and individualised ways of supporting people with intellectual disability to maximise their involvement in daily activities. This is different from 'active overnight support'.
Adolescents	Individuals in the phase of life between childhood and adulthood - roughly between the ages of 10-19.[2819]
Ageing SDA	Specialist Disability Accommodation (SDA) dwellings with a design category of Basic, and all Legacy stock. The Basic design category applies to SDA dwellings that were built before 1 April 2016 (Existing SDA) without specialist design features but with a location or other features that cater for the needs of people with disability and assist with the delivery of

Word	Definition
	support services. Legacy stock refers to SDA dwellings that are designed to house 6 or more long-term residents.
Annual Financial Sustainability Report (AFSR)	The AFSR provides an assessment of the financial sustainability of the NDIS and is required under the *NDIS Act* (Section 180B). It is produced using data at 30 June each year. A summary of each year's AFSR is included in the NDIA Annual Report.[2820]
Application Programming Interfaces (APIs)	A digital tool that allows software and digital product developers to plug into parts of existing digital systems when designing and building new tools and products. APIs can be used to enable data sharing between organisations and government agencies.[2821]
The Applied Principles and Tables of Support (APTOS)	The Applied Principles and Tables of Support (APTOS) are agreed between Australian, state and territory disability ministers. They set out roles and responsibilities of the NDIS and other service systems having regard to the funding and provision of supports to people with disability.
Assistance with daily life (ADL)	An NDIS support category that covers a range of supports, including assistance with self-care activities and assistance with household tasks, such as gardening or cleaning. It also includes community nursing supports, and short-term accommodation and assistance. Supported Independent Living (SIL) is also funded under this support category. The NDIA sometimes refers to the ADL support category as 'Core – Daily Activities' in published reports.
Australian Government Digital Service Standard Criteria	A set of best-practice principles for designing and delivering government services. It helps digital teams to build services that are user-friendly, inclusive, adaptable, and measurable.[2822]
Australia's Disability Strategy (ADS)	Australia's Disability Strategy 2021–2031 was signed by First Ministers of all Australian governments. It sets out a vision for an inclusive Australian society to ensure people with disability can fulfil their potential as equal members of the community.[2823]
Australia's Disability Strategy Advisory Council	The Advisory Council's role is to advise Australian governments and disability ministers on the implementation of the ADS. Advisory Council members are all people with disability.[2824]
Autism CRC	The independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.[2825]
Behaviour support or positive behaviour support	A range of proactive strategies implemented to identify and address the underlying causes of behaviours of concern through an individual

Word	Definition
	functional behavioural assessment and development of a positive behaviour support plan.[2826]
Behaviour support plans (BSP)	A document providing evidence-based strategies to help improve the wellbeing of the person with disability who has "complex behaviours of concern". It should be prepared in consultation with the person, their supporters and others who may assist to address their needs.[2827]
Best practice principles	Core principles that guide how early childhood practitioners work with families of children with developmental delay and disability. At its core, best practice is taking a family centred and inclusive approach. These were developed by Reimagine Australia (formerly Early Childhood Intervention Australia) in 2015.[2828]
Bilateral agreement	Bilateral agreements are between two parties and cover areas of shared interest to achieve a particular outcome. In the NDIS context, bilateral agreements are usually between the Australian Government and one other state or territory.[2829]
Block funded	Refers to a 'traditional' model of government funded service delivery where a department, agency or other service delivery organisation receives funding in a 'block', often based on fixed criteria with respect to expected numbers of clients, or services to be delivered over a given period of time. This is often contrasted with an activity based funding model where a department, agency or service delivery organisation receives funding based on the amount of services provided, and an assumed efficient price for each service. It is also distinct from an individual funding model such as the NDIS, where a participant receives an individualised budget that they can use to purchase market-provided services and supports.
Budget setting	In the NDIS context, budget setting is the process of determining the amount of reasonable and necessary support funding included in a plan.
Cabinet Minister	Along with the First Minister of a government, Cabinet ministers form the main decision-making group within executive government – the Cabinet. A Cabinet minister's role includes directing government policy and making decisions about issues, spending time considering and discussing current problems within their portfolio of responsibilities and how these can be solved, and presenting bills – proposed laws – from their departments.[2830]
Capability review	Capability reviews are assessments of an Australian Government agency's ability to meet future objectives and challenges. They are undertaken by the Australian Public Service Commission.[2831]
Capacity building	Increasing people's knowledge, skills and abilities. This can apply to an individual – for example, developing their skills in a certain area to allow

Word	Definition
	them to live more independently. It can also apply to a community as a whole – for example, building the capacity of organisations to be more inclusive.
Capacity building supports / budget	Funding that helps to build independence and skills. Funding is not flexible between support categories, and can only be used to purchase supports that are in the same Capacity Building category.[2832]
Care and support sector	The care and support sector describes a range of sectors involved in the provision of paid care and support. This includes aged care, disability support, veterans' care, and in some cases, early childhood education and care. For the purpose of this report, when we refer to the care and support sector, we do not include early childhood education and care.[2833]
Case conferencing	A semi-regular and more formal approach to checking in with families and the team around the child. The purpose is to understand progress, celebrate achievements and understand if any adjustments in approach are required. Families play a key role in design of the process.
Check in	A more regular and informal approach to checking in with families. This is to understand family and child progress, wellbeing, need for additional supports or revised approaches and understand any emerging issues.
Child health and development checks	Scheduled periods where child health and development is checked in the Health system. These are frequently completed by child and maternal health nurses, general practitioners and paediatricians.
Choice and control	The right to make decisions about what is important, to decide what supports are required and who will deliver them.[2834]
Citizens' jury	A citizens' jury provides the opportunity for citizens to learn about a complex issue, deliberate together and develop well-informed, common ground recommendations or solutions to difficult public issues. The citizens' jury process also allows decision-makers and the public to discover what people really think once they have heard from a balanced range of witnesses and taken a close look at a topic.[2835]
Commissioning	A process of purchasing supports or services from a provider or group of providers. The commissioning process could involve agreeing on what supports and services are delivered, as well as how much would be paid for delivering the support or service. Governments typically commission supports or services, but communities can also commission supports or services.
Commonwealth Mobility Allowance	A payment to people with disability or with other health conditions who need to travel for work or study but are unable to use public transport

Word	Definition
	without considerable assistance. It is not available for people already receiving funded supports from the NDIS.
Community control	The principle that First Nations communities have the right to participant in decision-making that affects their lives. Community-controlled organisations are organisations that deliver services to a community, and the community has say and control over what and how services are delivered by the organisation.[2836]
Community supports and activities	Supports and activities run by, in and for the local community. They include everything from local businesses to local sporting or recreational groups.
Compensation schemes	Schemes outside of the NDIS that provide payments for supports for losses or injury. These can include motor vehicle accident and compulsory third party schemes, workers compensation schemes, general insurance claims covering permanent illness or injury, and legally determined compensation arrangements.
Competitive approach	Market access settings where providers compete in the market to deliver supports to individual people, or a 'share' of the market. Providers can typically enter or exit a market at any time.
Complex communication support needs	People who need support to communicate to meet their needs. Some people may not use spoken language and will rely on other methods of communication such as pointing or gestures. Some people use technology or a communication partner to assist them in communication.[2837]
Complex Support Needs Pathway	A National Disability Insurance Agency term for NDIS planning for people with complex support needs.[2838]
Contestable approach	Market access settings where providers compete for a market – that is, providers compete with each other to deliver supports or services for all people in the market. Typically, 'the market' needs to be defined first. Providers typically enter or exit the market at set periods of time, and based on their ability to fulfil specific conditions or processes.
Continuum of support	Accessible, available and coordinated supports across mainstream, foundational and NDIS systems that mean children and families can access the supports that meet their needs.
Core support budget	One of the existing support categories that help participants with everyday activities. It is the most flexible, and most funding can be used flexibly across daily activities, consumables, social, community and civic participation and transport.[2839]

Word	Definition
Corrective measures (or safeguards)	Measures that resolve problems, enable improvements to be identified and avoid the same problems recurring (for example, complaints processes and compliance actions).[2840]
Council of Australian Governments	The Council of Australian Governments (COAG) was established in 1992 as the peak intergovernmental forum in Australia comprising of the Prime Minister, state and territory First Ministers and the President of the Australian Local Government Association (ALGA). Its role was to manage matters of national significance or matters that need coordinated action by all Australian governments. On 29 May 2020, National Cabinet agreed to the cessation of COAG. National Cabinet is the successor to COAG.[2841]
Council of Australian Governments Reform Council	Prior to its cessation in 2014, the COAG Reform Council assisted COAG to drive its national reform agenda by strengthening accountability for the achievement of results through independent and evidence-based monitoring, assessment and reporting on the performance of governments. The Council was funded by all governments but was independent of individual governments and reported directly to COAG.[2842]
Council on Federal Financial Relations	The Council on Federal Financial Relations (CFFR) comprises the Australian Government Treasurer and all state and territory treasurers. It is the gatekeeper of the Federation Funding Agreements framework and makes sure that agreements are negotiated and administered efficiently.[2843]
Cross-billing	In the NDIS context, cross-billing payments are made by the Australian Government to state and territory governments for supports provided to participants by state and territory service systems on behalf of the NDIS (for example, taxi subsidy schemes provided to participants).
Culturally and Linguistically Diverse	The Australian Institute of Health and Welfare define cultural and linguistic diversity (as encompassing), 'a range of aspects including a person's country of birth, their ancestry, where their parents were born, what language/s they speak, and their religious affiliation. There is no one definition of cultural and linguistic diversity.' The Diversity Council of Australia uses the term cultural diversity which, 'means having a mix of people from different cultural backgrounds – it can include differences in cultural/ethnic identity (how we identify ourselves and how others identify us), language, country of birth, religion, heritage/ancestry, national origin, and or race.'[2844]
Decision-supporters	Someone chosen by an individual to help them to make a decision. They do not make the decision on behalf of the individual and can be friends, family, carers, peer networks, advocates or support providers.[2845]

Word	Definition
Developmental and behavioural evaluation assessment	The proposed new approach to assessing the extent of developmental delay. These will be identified, tested, refined and validated with children and families, measurement experts and researchers, child development experts and representative organisations.
Developmental concerns	Delay/s in the development of a child younger than 6 compared to other children of a similar age, but where the delay does not meet the definition of developmental delay in section 9 of the *NDIS Act*.[2846]
Developmental delay	Delay/s in the development of a child younger than 6 that meets all criteria outlined in section 9 of the *NDIS Act*.[2847]
Developmental measures (or safeguards)	Measures that strengthen the capability of people with disability, their families and supporters, workers and providers to reduce the risk of harm and promote quality (for example, education, training and information).[2848]
Developmental monitoring	Process to observe how children are growing and changing over time and monitoring milestones in play, learning, communication behaviour and movement. Families and caregivers, with the right tools and information, are often best placed to do this monitoring as they spend the majority of time with their children.
Developmental screening	Developmental screening is a closer look at a child's development in areas of language, movement, thinking, behaviour, and emotions. This is usually undertaken by a professional with expertise in child development. It may involve brief assessment of the child or the caregiver completing questionnaire, formal evidence based checklists.[2849]
Developmentally vulnerable	Children who demonstrate a significantly lower than average ability in developmental competencies in particular domains (i.e. below the 10th percentile).[2850]
Digital Service Standard	A set of best-practice principles for designing and delivering government services that are user-friendly, inclusive, adaptable and measureable.[2851]
Dignity of risk	Supporting people to take informed risks to improve the quality of their lives. This means rather than seeking to eliminate all risk – which can be highly restrictive and out of proportion to the level of risk involved – the NDIS should work with participants to define acceptable risk levels to achieve their goals.[2852]
Disability	Used in the context of the internationally recognised social model of disability. This is a commitment by all Australian governments under Australia's Disability Strategy 2021-31. It describes disability as a social construct. Under this model, intersecting societal barriers are the obstacles to equal participation, not people's impairment.

Word	Definition
Disability Action Plans and Disability Inclusion Action Plans	A plan that details how an organisation will ensure its goods, services, workplace, premise and facilities are inclusive and accessible for people with disability.
Disability Reform Ministerial Council (DRMC)	Commonwealth, state and territory ministers with responsibility for disability policy meet regularly through the Disability Reform Ministerial Council (DRMC). It is established as a Ministerial Council with reporting lines to National Cabinet. For the purpose of the *National Disability Insurance Scheme Act 2013*, DRMC is the Ministerial Council with functions outlined in Part 5, s12.[2853]
Disability requirements	The requirements for becoming a participant of the NDIS under section 24 of the *National Disability Insurance Scheme Act 2013*.
Disability Support Pension (DSP)	In Australia, the DSP is a welfare benefit payable to people with disability who are assessed as having a low capacity to work.
Early childhood	The period of time between birth and 8 years old.
Early childhood approach	The way the NDIA helps children with disability and developmental concerns younger than 9 and their families access supports appropriate to their needs.[2854]
Early Childhood Early Intervention reset	A project developed by the NDIA to reset the approach to supporting children and their families. There were 23 recommendations developed and intended to be delivered by end 2023.
Early childhood partner	Organisations funded by the NDIA to deliver the early childhood approach for children with developmental delay and disability younger than 9.[2855]
Early Childhood Supports Module	Practice Standards that apply to providers registered to deliver early childhood supports to NDIS participants.[2856]
Early intervention	Providing support as early as possible to reduce the impact of disability or developmental delay and build skills and independence.[2857]
Early connections	Services provided by early childhood partners for children younger than 6 with developmental delay or children younger than 9 with disability and their families. May include a combination of services such as connections to community and other government services, practical information on child development, early supports, and assistance to apply to the NDIS.
Early intervention requirements	The requirements for becoming a participant of the NDIS under section 25 of the *National Disability Insurance Scheme Act 2013*.

Word	Definition
Early supports	A short-term program delivered by early childhood partners aimed at addressing specific concerns about a child's development and building family capacity.[2858]
Enrolled provider	Enrolment reflects the Review's recommendation and means a person or organisation that undergoes a process of enrolment to deliver lowest-risk supports under the National Disability Supports Commission (see Recommendation 17).
Evidence based support	Supports provided where there is evidence that the support is effective and beneficial for someone with similar needs and circumstance.[2859]
Existing SDA	An SDA dwelling that is enrolled to house five or fewer long-term residents and that was built before 1 April 2016 and that was used as disability related supported accommodation under a previous state, territory, or Commonwealth scheme. Existing dwellings must comply with the requirements of a New Build.
Family capacity building	Family capacity building is support for families of children with developmental concerns or disabilities. It can take a range of forms and include information, education, connections to other families, including for siblings and family leadership and empowerment.
Federation Funding Agreement	When an agreement involves funding from the Australian Government to the states and territories, it is covered under the Intergovernmental Agreement (IGA) on Federal Financial Relations. Under the IGA on Federal Financial Relations, payments to the states are outlined through schedules to one of five overarching sectoral Federation Funding Agreements or through one of the National Agreements.[2860]
Flexible budget	Funding covers what was formerly core supports and capacity building supports. Participants and their families can choose to use the funding flexibly.
First 1,000 days	The period of development between when a child is conceived through to their second birthday.[2861]
First 2,000 days	The period of development between when a child is conceived through to their fifth birthday.[2862]
Formal safeguards	Rules and the actions that are taken by organisations with formal responsibility for the safety of people with disability.[2863]
Foundational supports	Disability-specific supports that are available for and benefit people with disability, families and carers outside of NDIS individual budgets.

Word	Definition
Functional assessment	A functional assessment focusses on what a person can and can't do.
General foundational supports	Disability-specific supports that are available to benefit all people with disability, and where appropriate, their families and carers and people aged over 65. This includes information and advice and peer support.
Group homes	Homes where multiple people with disability, often five or more, live together under a single roof and receive support. They usually have a separate room for a support worker to provide onsite overnight assistance. Apart from staff, only people with disability reside in the dwelling. Each person has their own bedroom, while common areas, like a kitchen, bathroom or dining room, are shared with all the people living in the home. Group homes are generally provider-led, where the rhythm of everyday life is dictated by staff and service providers and residents have little or no say over who they choose to live with.
Guided Planning Questions	Structured questions asked as part of the pre-planning process for developing a plan. The questions inform the development of the Typical Support Package.
Home and community care programs	State and territory programs that deliver lower intensity disability care supports, such as personal and domestic assistance (including cooking and cleaning) to support people with disability live as independently as possible. Programs are targeted at people with disability aged under 65 and Aboriginal and Torres Strait Islander peoples aged under 50, who do not have an NDIS individualised budget.
Housing and living	In this report we use the term 'housing and living', rather than 'home and living', to directly recognise that there are two distinct but interrelated components to the supports of interest to this Review — housing supports (i.e. accommodation and the built environment) and living supports (i.e. support to assist participants with activities of daily living). There are complex interactions between housing and living supports. When working together well, these housing and living supports should create a sense of home for people with disability.
Inclusive and accessible	Inclusion is where everyone is treated equally and has an active role in society. Inclusive and accessible services and communities ensure people with disability can access appropriate support and participate as equal members of society.
Interdisciplinary teamwork	Multiple disciplines of professionals working with a child and having formal channels for communication between each other. The emphasis is having a formal structure to encourage coordination. However, the professionals

Word	Definition
	remain responsible for their respective disciplines and coordination is mostly limited to the formal channels.[2864]
Individual budgets	NDIS funding that is individually determined and made available to a single person.
Informal support	Support that participants receive from family, friends and the broader community, such as neighbours or work colleagues. It is called 'informal' because this support is not paid and not part of a formal agreement.
Information, Linkages and Capacity Building – (ILC)	ILC is a set of supports designed to increase the capacity of people with disability, their families and carers to achieve their goals and increase the capacity of the community to be more inclusive. Originally, ILC was known as Tier 2.
In-kind programs	Some pre-existing programs funded and provided by governments which provide reasonable and necessary supports to people with disability on behalf of the NDIS. When these supports are provided to a participant, the government that delivers the service receives a discount to their contributions to the NDIS to the value of the supports provided to the participant (i.e. the cost of the service provided to the participant is considered an "in-kind" contribution to the NDIS).
Initial supports	The way early connections were previously described by the NDIA.
International Classification of Functioning, Disability and Health (ICF)	A classification of health and health-related domains.[2865]
Intergenerational Report (IGR)	The Intergenerational Report is produced by the Australian Government. It projects outlooks for the Australian economy and the Australian Government's budget over the next 40 years. It examines the long-term sustainability of current policies and how demographic, technological and other structural trends may affect the economy and the budget.[2866]
Intergovernmental Agreement	An intergovernmental agreement (IGA) is an agreement made between the Australian Government and state and territory governments. While IGAs are not legally binding, they express the commitment of governments to work together on certain objectives or goals.[2867]
Intermediary	An individual or organisation who acts as a 'middle person' in assisting participants to interact or engage with others, including providers. Intermediaries in the NDIS include roles such as: local area coordinators,

Word	Definition
	early childhood partners, support coordinators, remote community connectors and plan managers.
Key worker	Another name for a Lead Practitioner.
Lead practitioner	An allied health, developmental or early childhood educator who is the main professional working with the family. They help coordinate the team around the child, provide information and advice, emotional support, identify and address needs and support the family to develop self-advocacy skills.
Legacy SDA	Dwellings that meet the Existing SDA stock requirements except that it is intended to accommodate more than five long-term residents.
LGBTIQA+SB	Lesbian, Gay, Bisexual, Intersex, Queer or Questioning, Sistergirl and Brotherboy. Sistergirl and Brotherboy are culturally distinct queer identities in First Nations communities. These terms are also used as terms of endearment throughout First Nations communities.
Local area coordinators	A contractor funded by the NDIA to deliver a range of coordination services in a particular location to people with disability aged 9 or older and their families.[2868]
Longitudinal data	Longitudinal data refers to a dataset where observations regarding a given individual, business or other unit of observation is collected repeatedly over time. This is often also referred to as panel data. A balanced panel implies that for each time period in the sample, there are a complete set of observations for each individual or observational unit in the panel. An unbalanced panel refers to the situation where not every individual or observational unit may record the full set of observations in every time period.
Mainstream housing	This includes home ownership, private rental market, affordable rental housing, and social housing (public and community housing).
Mainstream services	Mainstream services (also known as universal or essential services) are government services outside the NDIS that all Australians can access and benefit from, regardless of whether or not they have a disability. They include things like health care, education, transport, and employment services.
Market access settings	The conditions and processes about who (or which providers) can enter a market to deliver supports and services, which are additional to the broader regulatory requirements.
Market stewardship	The market stewardship role of governments is to support: informed participant choice; continuous improvement in service quality and

Word	Definition
	effectiveness; access to quality supports; and appropriate regulation and safeguards for people with disability. A number of government agencies have a market stewardship role of NDIS markets.
Medical model of disability	A deficit approach that considers disability as something that should be fixed.[2869]
Medical Services Advisory Committee	MSAC appraises new medical services proposed for public funding, and provides advice to Government on whether a new medical service should be publicly funded (and if so, its circumstances) on an assessment of its comparative safety, clinical effectiveness, cost-effectiveness, and total cost, using the best available evidence.[2870]
Medicare	Australia's universal health insurance scheme that provides guaranteed access to a wide range of health and hospital services at low or no cost.
Medicare Benefits Schedule	The MBS provides information on the arrangements for the payment of Medicare benefits. These arrangements operate under the Health Insurance Act 1973 (as amended).[2871]
Modified Monash Model (MMM) Classification	A way of categorising the remoteness of geographical locations in Australia according to the size and density of population in the location, and distance from capital cities.
Multi-channel digital payment system	Technology that enables buyers to pay for supports and services electronically (without cash) using more than one channel or method.
Multilateral agreement	A multilateral agreement is an agreement between the Australian Government and more than one other party. Within disability, multilateral agreements are agreements between the Australian Government and more than one state and/or territory
National Agreement on Closing the Gap	The National Agreement on Closing the Gap (2020) is a commitment by all Australian governments and First Nations people as represented by the Coalition of Peaks to work in new ways to drive better outcomes. These outcomes are represented through the four Priority Reforms and 17 socio-economic targets.
National Cabinet	National Cabinet is a forum for the Prime Minister, Premiers and Chief Ministers to meet and work collaboratively. It is the successor to the former Council of Australian Governments.[2872]
National Disability Data Asset	The National Disability Data Asset is a new way to connect information about people with disability. It will bring together de-identified data from Australian, state and territory government agencies.[2873]

Word	Definition
National Disability Supports Quality and Safeguards Commission (National Disability Supports Commission)	The new National Disability Supports Quality and Safeguards Commission reflects the Review's recommendation to expand the coverage of the current NDIS Quality and Safeguards Commission to regulate all Australian Government funded disability supports (see Recommendation 19).
National Injury Insurance Scheme	A program designed alongside the NDIS to provide lifetime care and support on a no-fault basis to individuals who suffer a catastrophic injury resulting in substantial and permanent disability. Intended to be established for four types of injuries: motor vehicle accidents, workplace accidents, medical accidents and general accidents (occurring in the home or community).
Natural safeguards	Actions and features that are part of people's day-to-day lives and support them to manage their safety (also called informal safeguards).[2874]
Natural settings	Places where children live, play and learn like the family home, school or early childhood education and care or community.
Navigator	Support available to all people with disability and children with developmental concerns. They will help participants get the best outcomes out of their budgets and help to connect to other supports. They will have genuine local connections, knowledge and links to local services.
NDIS Independent Advisory Council	The Independent Advisory Council (IAC) is established under Part 3 of the *National Disability Insurance Scheme Act 2013* and represents the participants' voice in the NDIS. The IAC has a statutory function to advise the NDIA Board on the most important issues affecting participants, carers and families.[2875]
NDIS outcomes framework	Surveys that measure the outcomes of participants and their family members and supporters over time. The surveys ask participants about how their lives are changing in areas like daily living, choice and control, health and wellbeing, relationships, community participation, work and learning. Family members and supporters are also asked about their experiences while caring for a person in the scheme.
NDIS portal	NDIA's information and communication technology (ICT) business system for participants, providers, NDIA staff and Partners in the Community
Needs assessment	A needs assessment focuses on what support someone needs to achieve the kind of life they value.
Needs Assessor	The individuals who will undertake the needs assessment process.

Word	Definition
Neurodiversity affirming	An approach that affirms an individual's neurodivergent identity by embracing their understanding of people and the world, without seeking to change or 'fix' them.[2876]
New Build SDA	An SDA dwelling that is enrolled to house five or fewer long-term residents and that was issued its first certificate of occupancy, or equivalent, on or after 1 April 2016. All its shared areas, and any bedrooms for use by SDA-eligible participants must comply with the Minimum Requirements for a Design Category other than Basic.
Nominees	A person appointed to act for or make decisions on behalf of a participant. Nominees can be appointed by participants or courts, and can be child representatives, correspondence nominees or plan nominees.[2877]
Non-SDA supported accommodation	Housing that is not SDA but is generally only accessed by people with disability, such as SIL homes and Supported Residential Services (SRSs).
Onsite Overnight Assistance	Refers a room used for one or more support workers for the purposes of providing either passive or active overnight support to one or more participants. This can be a separate room within a dwelling where one or more participants reside, or a separate room in an apartment complex where multiple participants have their own accommodation. SDA dwellings that have onsite overnight assistance have higher price limits, which are set out in the NDIA's SDA Pricing Arrangements and Price Limits.
PACE	NDIA's new information and communication technology (ICT) business system for participants, providers and NDIA staff, Partners in the Community. This is also referred to as the 'my NDIS portal'.[2878]
Participant	A person who meets the NDIS access requirements.[2879]
Participant journey	The path of interactions a person who meets the NDIS access requirements takes to access NDIS-funded supports.
Participant pathway	The interactions that a participant experiences in relation to the NDIS. This includes learning about the NDIS, applying for the Scheme and planning.[2880]
Participant Service Guarantee (PSG)	The Participant Service Charter includes timeframes for the NDIA's processes – set out under the Participant Service Guarantee and legislated through the *NDIS Act*. The NDIA must make decisions about access, plan approvals, plan reviews and nominee changes within these timeframes. This gives participants, families and carers greater certainty about how long processes will take. Each quarter, the Agency reports against Participant Service Guarantee timeframes in the Quarterly Report.[2881]

Word	Definition
Paediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT)	A functional capacity assessment used by the NDIA for children and young people.
Payment approach	The rules and processes around what the providers of a support or service is paid for delivering, and how they can be paid
Peer support	When people use their shared experiences to connect and help each other.[2882]
Peer worker	In the NDIS context, a person with disability in the NDIS workforce.
Person with disability	A person who has any or all of the following: impairments, activity limitations (difficulties in carrying out usual age-appropriate activities), and participation restrictions (problems a person may have taking part in community, social and family life).[2883]
Personal Care In Schools	Disability-related supports provided by state and territory governments to students to assist them with routine activities in school. This assistance generally covers meals, toileting and personal hygiene, dressing, mobility, along with complex supports (i.e. medicine, health supports).
Person Level Integrated Data Asset	PLIDA is a secure data asset combining information on health, education, government payments, income and taxation, employment, and population demographics (including the Census) over time.[2884]
Pharmaceutical Benefits Advisory Committee	The PBAC is an independent expert body appointed by the Australian Government. Members include doctors, health professionals, health economists and consumer representatives. Its primary role is to recommend new medicines for listing on the PBS.[2885]
Plan of action	A plan outlining how a participant would like to use their budget to meet their need and goals. It is an iterative document that can be updated as needs or preferences change
Plan inflation	In the NDIS context refers to the increase in plan values between participant plans, usually every 12 months.
Planning process	The process of developing a plan, including evidence gathering, planning meetings, the discussion of a participant's goals and aspirations and the statement of participant supports.[2886]

Word	Definition
Platform provider	In the NDIS context, this is a digital service which connects people with disability to service providers and workers.
Portable training	Ways to recognise learning, training and skills gained from working with more than one employer (including as a sole trader) and/or across the care and support sector
Portable leave	Ways to recognise and earn leave entitlements gained from working with more than one employer (including as a sole trader) and/or across the care and support sector
Positive rights-based	The culture and approach providers should have in place when delivering behaviour support and restrictive practices that is focused on improving the quality of life and protecting the rights of people with disability.
Preventative measures (or safeguards)	Measures that proactively regulate providers and workers to reduce the risk of harm and promote quality (for example, provider registration and worker screening).[2887]
Price bunching	The amount charged by providers for delivering supports is close to the price cap for the support.
Price cap	The maximum amount which providers can charge for delivering supports or services. This is also referred to as a 'price limit'.
Price settings	The rules and processes around how much sellers of products and services can charge the buyer for the products and services delivered. In NDIS markets, these are the rules and processes around how much can providers charge participants
Productivity Commission	The Productivity Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues affecting the welfare of Australians[2888]
Preferred provider lists	A list of providers with whom governments have negotiated a deal or agreement to deliver supports at better prices and/or with additional agreed standards. Other providers who are not on the list can still be selected to deliver supports or services.
Provider panels	An arrangement set up by governments with a group of providers to deliver supports or services in a certain location, for specific needs and/or using a specific approach. Providers can be selected from the panel to deliver supports or services.
Provider of last resort	A provider who is responsible for delivering an essential support or service when the market fails and there is no other timely way to deliver these

Word	Definition
	supports or services. The provider can be a government or non-government organisation.
Psychosocial disability	Arises from the interaction between a person with a long-term mental health condition (that may be episodic) and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.[2889]
Psychosocial supports	Supports for people with psychosocial disability to rebuild and maintain connections, manage daily activities, build social skills and participate in education and employment.[2890]
Quality	The extent to which supports meet or exceed a person's needs and expectations.[2891]
Plan reassessment	Where a participant's plan is looked at to see if it still working for them or needs to be changed. This can be planned or unplanned and can be initiated by the participant or the NDIA.
Reasonable and necessary	The test for determining whether a support should be funded by the NDIS in a participant's plan.[2892]
Regulation	Regulation is any rule where there is an expectation of compliance. Regulation can be formal or informal. Formal regulation includes things like rules and standards that are endorsed by governments. Informal regulation includes things like community attitudes and expectations. [2893]
Registered provider	A person or organisation that undergoes a process of registration to deliver supports under the current NDIS Quality and Safeguards Commission (or future National Disability Supports Commission).[2894]
Residential aged care	Aged care homes (sometimes known as nursing homes or residential aged care facilities) for older people who can no longer live at home and need ongoing help with everyday tasks or health care.[2895]
Restrictive practices	Practices or interventions that restrict the freedom of movement or rights of a person with disability.[2896]
Reviewing Actuary	The Actuary nominated under s180D of the NDIS Act[2897]
Risk-based approach or response	Approaches or responses that are informed by likelihood of harm occurring, and the magnitude and severity of that harm.[2898]
Risk-proportionate regulation	A risk-based approach allows a regulator to properly assess the risks of non-compliance and respond in a proportionate way to the harm being managed.[2899]

Word	Definition
Safeguards	Actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives.[2900]
Safety	Typically means being free from injury or danger. It does not matter if the injury or danger is intentional (on purpose) or unintentional (by accident).[2901]
Severity tool	An internal term used by the NDIA to describe assessment tools. An example of a severity tool is the PEDI-CAT.
Shared support ratio	Refers to the ratio of shared support (that could be delivered by one or more workers) and whether a participant is sharing supports with other participants in a 24/7 shared living arrangement. For example, a shared support ratio of 1:3 represents one participant sharing supports amongst 3 participants, including themselves.
Shared supports	Refers to shared living supports. The term is agnostic to the setting in which supports are delivered. Supports can be shared across a household living together under one roof, but they can also be shared amongst a resident group that have their own apartments in a single development or separate but co-located homes embedded within the community.
Share house	Similar to a group home in that multiple people with disability live together, sharing accommodation and living supports, but with fewer residents (generally no more than three). Share houses are also distinguished by being resident-led, where people have chosen who they are living with and there are mechanisms for shared decision-making over who provides their supports and how they live their lives. Those living in share houses have often been friends before choosing to live together.
Short Term Early Intervention	The former name for Early Supports.
Social model of disability	An approach that considers how an individual is disabled by their environment, rather than by their impairment. This might be due to factors like inaccessible physical environments or discrimination.[2902]
Social security	Social security refers to a system of social welfare benefits, payments or services available to people on the basis of particular socio-economic needs.
Specialist Disability Accommodation (SDA)	Housing with specialised design features available to participants with extreme functional impairment and/or with very high support needs. SDA funding can be included in a participant's plan and is paid directly to SDA providers to cover building and maintenance costs.

Word	Definition
Specialist School Transport	Disability-related transport supports provided by state and territory governments to students to safely transport students with disability to and from school.
Stated support	Funding can only be used for the specific purpose stated in the plan. These might include assistive technology or equipment, or Lead Practitioner support.
Substantially reduced functional capacity	One of the tests for determining whether someone meets the criteria to become a participant under section 24 of the *National Disability Insurance Scheme Act 2013*.
Substitute decision-making	Processes and arrangements that involve someone making decisions on another person's behalf. Can include appointment of guardians, administrators and financial managers.[2903]
Substitution effects	In the context of the NDIS, this refers to the replacement of particular government funded disability services, supports or assistive technologies outside the NDIS with broadly equivalent NDIS funded disability services, supports or assistive technologies.
Supported decision-making	Processes and arrangements that involve supporting individuals to make decisions about their lives, rather than making decisions for them.[2904]
Supported Independent Living (SIL)	A type of living support for participants with a higher level of support need – that is, those who require 8 or more hours of active support and/or supervision per day to complete daily activities as well as some level of support for the remaining hours of the day, i.e. 24/7 support. Generally, only participants over the age of 18 are eligible for SIL and support is shared, although not always.
Supports	Within the disability community and the NDIS, it means 'an activity or service that the NDIS provides funding for'.
Survey of Disability, Ageing and Carers	Conducted by the Australian Bureau of Statistics across Australia collecting data from three target populations: people with disability, older people, and people who care for persons with disability, long term health conditions, or older people.[2905]
Sustainability of the NDIS	Where the NDIS provides supports that are reasonable and necessary, demonstrably net-beneficial, and cost-effective. Governance arrangements provide clear accountabilities for managing lifecycle costs and financial risks. Scheme expenditure is predictable and provides benefits to participants, carers and the broader community, ensuring that Australians remain willing to contribute to it in an enduring manner.

Word	Definition
Targeted foundational supports	Early intervention and low intensity care supports that are primarily for specific groups of people with disability outside the NDIS who are in most need of additional support. Some participants may prefer targeted foundational supports from supports available as part of their individualised budget. This includes things like home and community care supports (such as shopping and property maintenance) for people with chronic-health related conditions and other disabilities, aids and equipment, early supports for children with development concerns and psychosocial support services.
Taxi subsidy schemes	Financial assistance provided by state and territory governments to people with disability that subsidises their taxi travel needs.
Transitioned participants	Participants who were accessing defined Australian Government, state or territory specialist disability support programs in operation prior to the NDIS and entered the scheme through Bilateral Agreements between the Australian Government and individual states and territories.
Transdisciplinary care	Refers to multiple disciplines of professionals working together with a child and family as a collaborative team. Removing the focus on individual roles or disciplines for professionals is a feature of the approach. This emphasises working across disciplinary boundaries. A key worker plays a primary role in coordinating the intervention and delivering most (if not all) of the intervention.[2906]
Thin markets	A market where the supply or availability of supports is too low, or the demand for supports is too low or spread out for competition between multiple providers to occur. In the NDIS, thin markets most commonly occur in rural and remote areas, but can also occur in metropolitan areas, where there is a specific support need – such as for specialist or culturally informed services.
Third party online platform	A digital service which connects participants with service providers (including independent contractors). A third party online platform is a type of platform provider.
Tier 2	The term Tier 2 originated from the 2011 Productivity Commission report into Disability Care and Support – which set out the design of the NDIS. Tier 2 referred to the types of supports people with, or affected, by disability may need to access. This included things like information, linkages and referrals. In 2015, all governments agreed to rename Tier 2 as Information, Linkages and Capacity Building (ILC).[2907]
Transitioned participants	Participants who were accessing defined Australian Government, state or territory specialist disability support programs in operation prior to the

Word	Definition
	NDIS and entered the scheme through Bilateral Agreements between the Australian Government and individual states and territories.
Typical Support Package	An indicative funding amount generated based on information gathered from a participant. The NDIA uses this calculation to help them decide what supports to include in a participants plan.[2908]
Unauthorised restrictive practice	In the NDIS, this is where a restrictive practice is used by a provider or worker without receiving authorisation from the relevant state or territory authority, or not used in accordance with a behaviour support plan.[2909]
Unregistered provider	Under current arrangements, a provider that supports a participant, but is not registered as an NDIS provider.[2910]
Utilisation rate	Refers to the amount that a participant spends of their allocated NDIS plan budget, usually expressed as a percentage.
Western concept	Consistent with the social model of disability, the recognition of disability as a 'western concept' acknowledges that 'disability' as it has been traditionally understood and represented in Australian policy and systems is based on a western cultural ideals and values.

Appendix B: Co-Group Feedback to the NDIS Review Panel

Co-Group Feedback to the NDIS Review Panel – Friday 13 October 2023

About this document

This document describes a set of principles for reform and considerations for implementation developed by the NDIS Review Co-Group (Co-Group) in response to ideas to reform the participant pathway presented by the NDIS Review.

This document and the structure of the Co-Group's output was prepared by the NDIS Review Secretariat, based on discussions with, and input from, the Co-Group.

The principles and considerations define the things the Co-Group believes are critical for the NDIS Review Panel to consider when delivering their final report and making recommendations on implementing reform to the participant pathway.

The two high-level ideas discussed in detail are set out below.

Idea 1*: A simpler way to gather information about people and their needs.*
Assessment of need, separation of budget setting and planning

Idea 2*: A better way for participants and families to get the support they need.*
Navigation and community capacity building

In the course of their work, the Co-Group also discussed considerations for how accessing the NDIS should work in the future, and other reforms that are critical to the success of the participant pathway. Principles and considerations for these issues are also set out below.

About the process

Co-Group members participated in seven sessions with the NDIS Review Secretariat and worked closely with a Panel member representative and a Co-Facilitator with lived experience and deep sector expertise. The eighth session involved a discussion with the NDIS Review Panel. The Co-Group also considered the feedback from four lived experience working groups and two working groups with expertise in service delivery and operation of the participant pathway.

The two ideas set out in this report are parts of the design of the future NDIS participant pathway that have a significant impact on all people with disability, their families and/or supporters and the broader disability community. The process for testing these ideas was developed to understand 'what' people with disability and the sector want and 'how' it might be possible to deliver this, while balancing the difficult trade-offs governments must make.

The Co-Group recognises that providing the detailed principles and considerations for reform in this document is only the first step in what will be a longer process of transition and

implementation of reform. Implementation of these reforms will require detailed planning and collaboration with those with lived experience, sector and technical expertise to ensure the NDIS Review Panel's final report and recommendations are implemented carefully and effectively, in collaboration with and accountable to people with disability.

Co-Group Principles for Reform & Considerations for Implementation

The Co-Group's Principles for Reform, Considerations for Implementation and Recommendations on Intersectionality are set out below in the following structure:

- Overarching principles for reform
- Considerations for reform outside the participant pathway
- Applying to the NDIS
    - o Specific Principles for Reform related to applying to the NDIS
    - o Considerations for Implementation
- Gathering information on need and setting budgets
    - o Specific Principles for Reform related to gathering information on need and setting budgets
    - o Considerations for Implementation
- Navigation
    - o Specific Principles for Reform related to Navigating the NDIS
    - o Considerations for Implementation
- Recommendations on Intersectionality

Overarching principles for reform

1. **Simple and Transparent:** Reforms are practical with immediate benefits and longer term outcomes that are clearly defined and monitored. The experience of accessing the NDIS, using NDIS funds and interacting with the NDIS is simple and transparent for everyone as changes are implemented over time.
2. **The NDIS is accessible and works for everyone:** The accessibility of all services, processes, tools and templates are designed with people with disability with a focus on people who have the highest support needs and find it most challenging to navigate the NDIS. This includes communication, documentation, and physical and cognitive accessibility across all written, online, face-to-face and phone interfaces and all other distribution channels.
3. **Good outcomes:** The planning process is consistent, meets the individual needs of people with disability and leads to equitable outcomes that are important for participants and contributes to a sustainable NDIS. Feedback about the planning process is used to continuously improve the planning process. A sustainable NDIS is defined with reference to the rights, needs and interests of people with disability.
4. **Choice & Control:** Reforms to the way people interact with the NDIS are designed with people with disability to ensure that participants have genuine choice and control over the supports

they receive and the service providers that deliver them, including separation of supports between different providers.[1]

5. **Build Trust:** Procedural and/or operational changes to the NDIS are designed, tested, monitored and communicated in a way that builds and promotes mutual trust with participants and provides the opportunity for ongoing feedback and continuous improvement.

6. **Recognise intersectionality through all aspects of the participant journey:** All people with disability must be able to access safe, equitable services that respond to their needs and uphold their rights. Governments, policy makers and front line staff must be trained to provide culturally responsive, trauma-aware and healing informed responses to overlapping forms of marginalisation and intersectional needs. This includes identity-based attributes (cultural or ethnic identity, sex, sexuality, or gender identity), and life and experience-based attributes (age, homelessness, or migration and visa status).

7. **Minimise burden on participants:** Information is collected only when it will be used to make decisions relevant to potential or current Participants or to broader NDIS scheme planning; existing information is reused, where relevant, with the permission of participants and their supporters. Participants and their supporters are clear on how information will be used and stored, and have rights to correction and erasure of existing information.

8. **Test and refine all reforms with people with disability:** The design, testing and monitoring of the effectiveness of processes, tools and templates must involve the genuine and meaningful participation of people with disability. This includes people with complex disability and communication needs, and people from other marginalised groups.

Considerations for reform outside the participant pathway

Outcomes Measurement: The NDIS must define which tools and data sets should be used to measure unmet need (including emerging and future needs), outcomes, wellbeing, inclusion and rights (such as ABS, AIHW, disability wellbeing framework).[2] The NDIS should be using data as part of a continuous cycle of improvement. This reporting should be made publicly available for transparency. Data must be comprehensive and disaggregated by participant characteristics to ensure that unmet need among marginalised cohorts is identified.

Interfaces with other systems: The role of states and territories, other systems (for example, health, education and employment) and community organisations must be clearly defined and agreed, underpinned by safeguards, complaints mechanisms and measurable outcomes.

Understanding the gaps: The Panel must provide a strong recommendation that Government should invest in better understanding the experiences of people with disability who are not participants, including those who test and are denied access to the NDIS. This should include what changes are needed to make sure their needs are met. Data should be disaggregated by gender, age, disability, CALD status, First Nations status, geographical location, and living or residential setting. This data to understand the gaps should be tracked and published for transparency. Improved data collection will guide both better policy development and implementation. Valid,

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[1] See recommendations 7.41 a. & 10.2 in DRC Report.

[2] Also see recommendations 10.20, 10.21, 10.23 &10.26 from DRC report.

reliable data will assist with not only understanding current unmet need but also support planning for emerging and future need.

Stewardship of NDIS Review Recommendations and related disability reforms (Disability Royal Commission Recommendations and the implementation of the Australian Disability Strategy): Governments should create formal mechanisms for the disability sector to provide expert advice on the implementation of recommendations. This should include priority-setting, oversight and monitoring of reform progress, with clear lines of accountability. These mechanisms should be designed with Disability Representative Organisations (DROs) and include majority representation of people with disability, particularly people who access support through the NDIS. They may include formal oversight bodies as well as opportunities for Secondment and exchange of expertise between DROs and the public service.

Workforce capability uplift: Government needs to invest in comprehensive training and support for NDIS staff, educators, health professionals, and other professionals involved in supporting the represented communities at all life stages. In line with the CRPD, appropriate training should be promoted for "professionals and staff" involved in all disability assessments "so as to better provide the assistance and services guaranteed by those rights" (Article 4 and 13 CRPD). This might include training in the interactive and contextual concept of disability, awareness of disabling barriers and the social model, the CRPD, legal capacity and a person-centered approach.

Applying to the NDIS

Specific Principles for Reform, when applying to the NDIS

Note: Principles 1, 2, 7 and 8 are particularly relevant to applying to access the NDIS - simple, transparent, valid, reliable processes are needed that are accessible to everyone and minimise burden on NDIS applicants.

(1) Simple & Transparent

People are linked to supports through the systems they currently use: People with a disability and their families and supporters are able to find information and be connected with a Navigator through systems that they are already using such as general practitioners, the education system, employment, justice and child protection systems as well as peer support and advocacy services in the community.

People are linked with a Navigator as early as possible: Government must take a funnel approach where the initial goal is to reach as many people who need support as possible. The level of support required must be identified and people are linked to support they need, with those with the highest needs receiving NDIS packages.

(2) The NDIS is accessible and works for everyone

Pre-access support to understand the NDIS: People with disability and their families and supporters have access to information about disability support tailored to their needs and

circumstances. For example, accessible multi language materials about what the NDIS is and how to access general navigation support is available on multiple platforms and formats.

Keeping the access process simple: Most access decisions are made based on information from trusted professionals, participants and nominees. Applications are considered by an appropriately qualified professional who is visible to the applicant throughout the process. Additional evidence is only required when access decisions are more complex

No costs to access reports and specialists: Government covers any costs for assessments and reports required to access the NDIS, including any related travel and associated costs for specialists to visit people in rural and remote communities and other thin markets.

Support during the access process: Appropriately qualified Navigators provide support to applicants through the access process including help to complete forms or participate in processes and self-report. Particular attention is given to people who have difficulty accessing formal systems and supports, or experience additional barriers due to other disadvantage.

Culturally appropriate and culturally safe access processes: Any new criteria for access need to align with cultural models of inclusion of disability, centring human rights to recognise First Nations people and people from culturally diverse backgrounds with disability as having a fundamental right to full societal participation on an equal basis with non-disabled people.

(5) Build Trust & (7) Minimise burden on participants

Prioritised information from participants and trusted professionals: Input from participants (including self-reporting on assessment questions) and the people they trust is prioritised in assessment of eligibility. Trusted professionals do not need to be health professionals.

(8) Test and refine all reforms

Tailored assessments for access: There is no off-the-shelf assessment process that works for the majority of people seeking access to the NDIS. Consideration of tools and processes needs to build on existing reliable and validated tools and be done with the disability community, including people who experience overlapping forms of marginalisation whose scores on assessments may be impacted by gender or cultural bias.

Considerations for Implementation

Support for Decision Making: Most people receiving supports from the NDIS need support for decision making and the NDIS needs to be designed so that it is equitable for everyone. This includes by implementing a supported decision-making framework that recognises support for decision making and access to individual advocacy is a right.

Easy access to information about disability supports: People with disability must be able to get information about how to get support through the NDIS as well as other supports in the community. Nationally branded and locally designed, accessible physical and online spaces in the community must be available to everyone to easily find out about disability supports.

Information and support for people who are not eligible for funded packages:
People who are found to not be eligible for funded NDIS support should be given clear and timely information and explanation. There must be a clear process around how to challenge this decision. People who have been denied access should be linked to the Navigator who will support them to access foundational and community supports.

Costs associated with access can vary: Costs associated with accessing the NDIA will be different for different people. For people with disability in remote communities this will include the costs relating to travel to see specialists.[3] For participants with disability that can't travel, the NDIA will cover the cost of a specialist travelling to meet participants where they are. For participants who speak languages other than English, there may be costs associated with translation and interpreter services. Regardless of costs, the Government must ensure people are not out of pocket due to trying to access the NDIS.

Idea 1 - A simpler way to gather information about people and their needs.

Assessment of need, separation of budget setting and planning

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- Simplifying the way the NDIS gathers and updates information about people with disability.
- Reducing the requirement for multiple costly reports and other forms of evidence; reducing real costs and related burdens.
- Working with people with disability and families to learn how the NDIS can build and demonstrate trust in gathering information about needs, strengths and life context.
- Working out funding for participants based on their needs, strengths and life context. Investing in understanding and learning from people with disability and their families and supporters about what works for them.

Gathering information on need & setting budgets

Specific Principles for Reform related to information and budget-setting

> *Note: Principles 1, 3, 4, 5, 7 and 8 are particularly relevant to gathering information on need & setting budgets; simple, transparent processes are needed that build trust and minimise burden on NDIS participants. This includes ensuring needs assessments are accurate and deliver good outcomes, allow for genuine choice and control and are tested, refined and accountable to with people with disability.*

8. *(1) Simple & transparent*
Transparent budget decisions: Budget calculations are transparent with sufficient information on how decisions are made, so that participants understand how their budget was constructed, and can dispute decisions.

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[3] See recommendation 10.10 in DRC report.

9. (3) Good outcomes

Needs based budgets: The NDIA should use the information they gather about people's needs including from self-assessment, trusted professionals, family and/or supporters, and outcomes of the need assessment to determine a budget at a whole-of-person level.

Accurate budget setting: The way the NDIA decides the level of support for a participant is applied consistently and leads to funding that enables them to meet their needs.

Opportunity for Review: Participants are provided draft budgets for their review prior to their finalisation. Participants also have an opportunity to have their budget reviewed if they feel it is incorrect or insufficient for the supports they require.

10. (4) Choice and control

Empowered participants: Participants have flexibility and choice within a set budget to allow them to choose the supports they need and the service providers who provide those supports.

11. (5) Build trust

Prioritised information from participants and trusted professionals: Input from participants (including self-reporting on assessment questions) and the people they trust is prioritised in assessment of need. Trusted professionals do not need to be health professionals.

Highly valued lived experience: Participants and families are heard when there are issues with an assessment process and any concerns about the accuracy of the assessment are clearly addressed.

Holistic needs assessment: Any needs assessment process must be grounded in human rights, ethical considerations and captures people's support needs, life stage, life circumstances and life transitions, and carried out by a skilled and well trained professional who can build and demonstrate mutual trust with the participant.

12. (7) Minimise burden on participants

Support to gather information: Disabled people need to be able to actively in generating the evidence on which their needs assessments are made, for example, through the availability of peer-supported self-assessment.

Information provided once and reused: All information provided previously (including as part of access to the NDIS and in previous planning meetings) is taken into account without the participant having to repeat themselves. Participants have a right to correction and erasure of existing information where it is no longer relevant (for example, their disability is a progressive disease or they have undergone gender transition).

Flexible assessment processes: A one size fits all approach will not work for everyone. Assessments are conducted flexibly to respond to participants' needs including variations in the process where required. Consideration must be given to validity and reliability of tools, accessibly, communication and other intersecting needs.

13. (8) Test and refine all reforms

Continuously improved information gathering: There is robust testing and refinement of any process to translate needs into budgets with the disability community and the assessors who will conduct needs assessments to ensure participants are getting access to the support they need.

Considerations for Implementation

Trauma informed approaches must be central: Many people with disability have a history of trauma they have repeated many times over and the approach to understanding the unique needs of participants and their families and/or supporters must reflect this.

Appropriately skilled needs assessors: The professionals conducting needs assessments should have formal qualification an allied health, social services, or disability practice with a graduate certificate or similar in disability studies at a minimum. Assessor's must be able to critically analyse the social position of people with disability, understand and address ableism, understand and implement the UNCRPD and balance clinical knowledge with embodied social knowledge and intersectional perspectives.

Needs assessments must be tailored to be accessible: The needs assessment must be designed to be appropriate and accommodate people who have complex communication needs and those with low levels of literacy, including all accessible forms of communication. Alternative approaches need to be available if a needs assessment would create risk to the individual or to the assessors.

Informed participation in the process: Participants must have access to the outcomes of their assessment as soon as it is completed and participants, nominees and/or navigators can initiate a review if there are concerns about the outcome. Participants need to understand how assessors and evaluators fit not only within the NDIA but into the system wide approach to regulating disability services.

Budget setting and needs assessment must not be based on diagnosis: the cost of accessing the systems required for getting a diagnosis must not be a barrier to people getting a needs assessment that reflects a whole of person perspective. People with similar needs and circumstances have equitable budgets that are appropriate for their individual needs and circumstances.

Start with existing assessment processes: Existing processes to measure support intensity and needs assessment processes are not necessarily fit for purpose. The design of disability assessments must be based on a social and human rights model of disability, and incorporate this approach into the practical implementation. Both redevelopment and/or adaptation of existing tools and development of new tools must build on existing research and reliable and validated tools that are in use in other sectors.

Consistent communication with the community: Recommendations on the proposed needs assessment that are implemented by Government must be clearly communicated with community and articulate who performs the assessment, the methods that will be used to build trust provide reassurance that another version of independent assessments is not recommended.

Idea 2 - A participant-centered way to build a plan and put it into action.

Navigation and Community Capacity Building

▪ Giving participants more support and flexibility to create their preferred plan within a set budget. The budget is set in line with each participant's needs
▪ People with disability are supported by someone who can provide evidence-informed support. This support can also provide examples of good plans and good local services that have worked for other people in similar contexts.
▪ People with disability are supported by someone with strong local connections and the power to engage with non-NDIS services. This will help make sure people with disability are connected to the right supports and services to get the best possible outcomes.

Navigation

Specific Principles for Reform related to navigating the NDIS

Note: *Principles 2, 3, 4 and 8 are particularly relevant to the role of the NDIS Navigator - a clear role, simple accessible processes and a strong emphasis on choice, outcomes, evaluation and refinement*

14. (2) The NDIS is accessible and works for everyone
A single point of contact: Navigators must be a single point of contact, supplemented by specialist navigation (with expertise in specialist areas and the needs of marginalised cohorts), and provide continuity of support. As far as possible, people should be able to keep the same Navigator throughout their journey unless a request for change is made.

15. (3) Good outcomes
Transition to Navigation supports: Grandfathering existing support coordination and partner functions that are working well to support a careful transition to Navigation supports that ensures continuity of support. This means that people who are happy with their support coordinator or partner, will not lose that support.

Disability Expertise: Navigators have professional expertise and/or lived experience of disability (where possible), are trained in trauma-informed approaches and supported decision making and to provide culturally safe supports and demonstrate delivery of service in this way. People with lived experience of disability are prioritised for these roles.

Quality standards: Navigators must provide a high quality of service to people with disability. Feedback from people with disability and their families and/or supporters must be actioned. Appropriate safeguards and quality assurance mechanisms must be in place.

16. (4) Choice & control
Flexible service delivery: Navigation support is provided in ways that ensure all communities can access the information they need in ways that work best for them. For example, navigation may be provided face to face, online, one to one, groups, phone, peer navigation

Meeting people where they are: Participants can make a choice about how much support they access from the Navigator, some people may require very little support and others may seek or require more intensive supports. Navigators will play a key role in building capacity of all people with disability to make their own decisions.

17. (8) Test & refine all reforms

Local design with national oversight: Navigation supports must be designed and commissioned to ensure that the services and supports meet the needs of people with disability in each community (including marginalised cohorts). National oversight must provide a framework and overarching principles to ensure appropriate and consistent standards of service delivery are met.

Evaluation and refinement of navigation functions: As the navigation function is tested and rolled out by the NDIA**,** there needs to be ongoing evaluation and refinement to ensure participants and people with disability are getting access to the support they need. People with disability must participate in the oversight and evaluation.[4]

Considerations for Implementation

Participants, their nominees and/or their navigator must be able to initiate an updated assessment of need easily and the burden to provide new information must be minimal: Participants can be referred back to an assessor for a significant change of circumstances and at transition-points that impact their budgets. Wherever possible, previous assessment information will be reused for this process and only necessary new information will collected.

Regular check-ins and more consistent support: Navigators will provide participants with more regular check-ins to support connections to services that are working, and to help support people to use their funding in a way that meets their goals.

Quick access to critical support: There needs to be a rapid approval pathway for temporary supports critical for safety and wellbeing available to all participants, including at times of crisis or unexpected life transition. There is need to identify how participants can access this pathway and get timely responses.

Using existing support networks: Expertise in different organisations that are acting either formally or informally in delivering an aspect of the navigator role currently, should be supported to continue. This includes the option to use peer-support as part of navigation and having access to specialist information and feedback on key issues (for example, housing, education and employment).

Providing direct support and coordination: Navigators should also be able to direct people to non-NDIS related supports they require at certain life stages. Such as supporting parents find

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[4] Suggest alignment with recommendation 10.30 in DRC report so that it extends to include navigation function in using data to respond to service quality and make improvements, plus build capacity in navigation workforce.

advocacy supports when their child is either starting primary or high school or supporting young people to learn more about higher education and job market when they finish school.

Employing people with lived experience: There should be a focus on employing people with lived experience across the NDIS system, including within Navigator roles and NDIS providers – with a minimum quota for all participant-facing roles.

Support is available when things go wrong: Navigators are a resource that people can use when they want to make a complaint, raise concerns of safety of supports, or report fraudulent activities by providers. They can connect people with disability, to disability advocacy services who can provide advocacy support and assistance.

A new approach is needed: The transition to Navigation should not simply allow for existing Partners in the Community to transfer into Navigation – a new approach is needed.

Recommendations on Intersectionality

In addition to the principles and consideration provided above, Co-Group presented to the NDIS Review Panel on 3 October the following recommendations that relate specifically to intersectionality, noting that we believe that it should be across all elements of the participant pathway. We know that certain groups of people experience different barriers to accessing the Scheme due to disadvantage at the intersections of both their disability and other attributes.

For example, First Nations people, people from culturally and linguistically diverse backgrounds, women, children and young people and LGBTIQA+ people may experience additional barriers to assessments to prove eligibility for the Scheme. Some cohorts may be less likely to have informal supports, including older people who have elderly parents, and children, young people and members of the LGBTQIA+ community who don't have the support of their families.

By way of example, we want to highlight four types of barriers faced by these cohorts.
1.	Many of these groups may **not have access to documentation** required to prove eligibility, including due to age, lack of access to healthcare and other service systems, disconnection from family or community, and migration or displacement.

2.	**Access to services to assist with navigating the NDIS process** might be difficult due to homelessness, a lack of digital or English literacy, a lack of services in rural and remote areas, a lack of culturally safe services, or fear of harm or discrimination on the basis of sexual or gender identity, particularly in faith-based organisations.
3.	**Access to NDIS services delivered in other institutional settings** (such as the justice system, aged care environments and hospitals) might be difficult due to institutional bias and inadequate information.
4.	We know that these cohorts have **different experiences of the supports and services that they do receive** and are at **greater risk of harm within service settings.**

The Co-Group recommend that the NDIS Review Panel consider and address the unique barriers that some communities face in relation to access to the NDIS and funding of supports and services. Among other things, this requires the following.

- Fully implementing the NDIS culturally and linguistically diverse strategy as planned and approved by NEDA, and fully implementing the NDIS LGBTQIA+ Strategy.
- Developing and implementing a new and fit for purpose First Nations Strategy, in partnership with the First Nations Advisory Council.
- Developing an NDIS Gender Strategy.
- Establishing an intersectional working group at Federal and State and Territory levels to inform policy and action and ensure that they are fit for purpose for marginalised cohorts.
- Ensuring the meaningful participation of members of the represented groups, in advising on all NDIS policies, programs and frameworks, as well as Tier 2 supports and services.
- Providing support and funding for crisis and transition points in participants' lives, not only in relation to life stages like leaving school and ageing, but also undergoing gender transition, coming out as LGBTQIA+, and experiencing homelessness, gender-based or family violence, divorce, and climate-related emergencies.
- Improving data collection across both NDIS and non-NDIS systems, including by:
  o Extending the NDIS outcomes framework survey data collection to include NDIS applicants found ineligible. Without this, people who experience overlapping forms of disadvantage will continue to fall through the cracks.
  o Collecting and reporting on data that is broken down by participant characteristics at all points of interaction with the NDIS, to understand and address unmet need effectively. For example, the NDIS Quarterly Reports provide data on participant characteristics, but gender and LGBTIQA+ identities are not included. The Reports also provide the number of complaints and incidents reported, but no information on the participant characteristics associated with that data. We know that the participants who experience overlapping forms of disadvantage are at the greatest risk of harm within service settings. Improving data collection on intersectional identities is one of the recommendations of the Royal Commission, with disaggregated complaints and reporting data addressed at Recommendation 10.26.
  o Investing in national and regional mechanisms to prioritise and act on the voices of the represented groups, by collecting evidence directly from these communities.
  o Implementing the recommendations of the Australian Institute of Health and Welfare, including by tracking the pathways and outcomes of children through different systems with improved data linkage, and addressing the dearth of data in relation to women with disability.
  o Using the improved data collection to guide policy development and implementation. Strong data can assist with not only understanding current unmet need but also supporting planning for emerging and future need.
  o Upskilling and empowering the NDIS workforce to support the unique needs of these groups during the access and budget setting process, including through sector capacity building. This should include:
    ▪ Improving cultural competency and cultural safety for generalist advocacy services, supported by appropriate funding and lead by First Nations, culturally and linguistically diverse and LGBTIQA+ organisations (consistent with the recommendations of the Royal Commission).
    ▪ Employing people with lived experience across the NDIS system, including within Navigator roles, Support Co-ordination and NDIS providers – with a minimum quota for all participant-facing roles.

- ▪ Investing in comprehensive training and support for NDIS staff, educators, health professionals, and other professionals involved in supporting the represented communities at all life stages. Training should address the systems of oppression that disadvantage these cohorts, including racism, ableism, sexism, colonialism, ageism, classism, queerphobia, transphobia and intersexphobia.
- ▪ Returning genuine choice and control to participants and their families and supporters and providing assurance that participants won't be worse off due to price gouging, fraud or profiteering by providers, specialists or areas of the workforce outside of the participants' control.
  Connection to over-arching principles

The Panel will have noted that one of the eight overarching Co-Group Principles for reform is prima facie recognising intersectionality. In addition, we would like the Panel to note that these intersectional matters are intimately linked to the principles of the NDIS being accessible and working for everyone, and minimising burden on participants.

Co-Group Membership

Members of the co-group included representatives from Disability Representative Organisations as well as individuals. The members of the co-group were:

- Katharine Annear - Autistic Self Advocacy Network of Australia and New Zealand
- Tracylee Arestides - Australian Federation of Disability Organisations
- Jane Britt - People with Disability Australia
- Jax Brown OAM LGBTIQA+ disability advocate
- Kelly Cox - First Peoples Disability Network
- Sophie Cusworth - Women with Disabilities Australia
- Deborah Fullwood – Lived Experience
- El Gibbs - Disability Advocacy Network Australia
- Dominic Golding - National Ethnic Disability Alliance
- Dula Hettiarchchi - Children and Young People with Disability Australia
- Catherine McAlpine - Inclusion Australia
- Darryl Steff - Down Syndrome Australia

Appendix C: Technical Analysis using Person Level Integrated Data Asset

The Review undertook exploratory analysis using the Australian Government's Person Level Integrated Data Asset (PLIDA) data to gain insights on the impact of the NDIS on participant and carer lives. By linking information on health, education, government payments, income and taxation, employment, disability and the Census over time, we were able to better understand the impact of the NDIS on participants and family member income, use of subsidised healthcare services, and psychological wellbeing.

An important advantage of administrative datasets is the ability to observe the evolution of outcomes for participants and their family members before and after they or a household member becomes an NDIS participant. Using, contemporary evaluation techniques, our analysis focused on assessing the *causal* impact of being in the NDIS on participant and family member's income; Medicare benefit spending for participants; as well as participant consumption of nervous system medications such as anti-depressants as an indicator of subjective wellbeing.

Overall, our analysis suggests the NDIS is starting to deliver some of the envisaged benefits for people with disability, their family members and supporters. While these benefits appear relatively modest at this stage, they are likely to represent a relatively conservative, lower-bounds estimate of relevant NDIS net benefits. The full scheme has only been operating for three years and benefits will continue to increase over time, given the lifetime approach to participant support.

There is evidence the NDIS is helping participants who have employment objectives

For participants with employment objectives, Figure C1 shows the NDIS is most likely supporting earnings levels for participants broadly in line with pre-NDIS earnings, and also population wide average earnings. Autistic participants with work objectives appear to have experienced the greatest benefits through higher earnings levels, bringing their incomes into line with average income levels for the population as a whole. These earnings benefits are significant with NDIS support helping people to increase their earnings by 11 per cent on average for autistic participants, and by as much as 30 per cent after four years on the scheme.

We believe these results are likely due to the limited support available to autistic adults before the NDIS relative to other disability cohorts. Given inherent limitations in the administrative datasets used, our view is that these results predominantly reflect participants already in employment working more hours and or at higher wage levels, rather than increases in earnings as a result of moving into employment from unemployment or outside of the labour force.

Figure C1: Proportional difference in real 2020-21 NDIS participant total income relative to their year before entry[2911]

(a) NDIS Participants

(b) Autism NDIS Participants
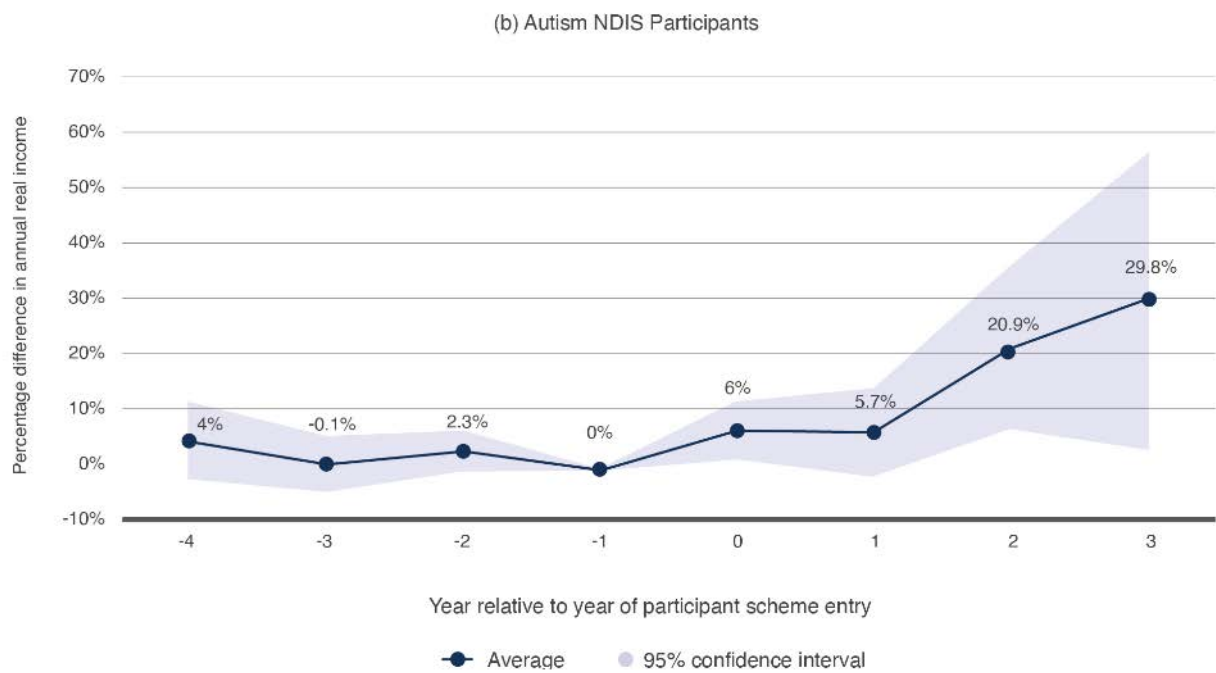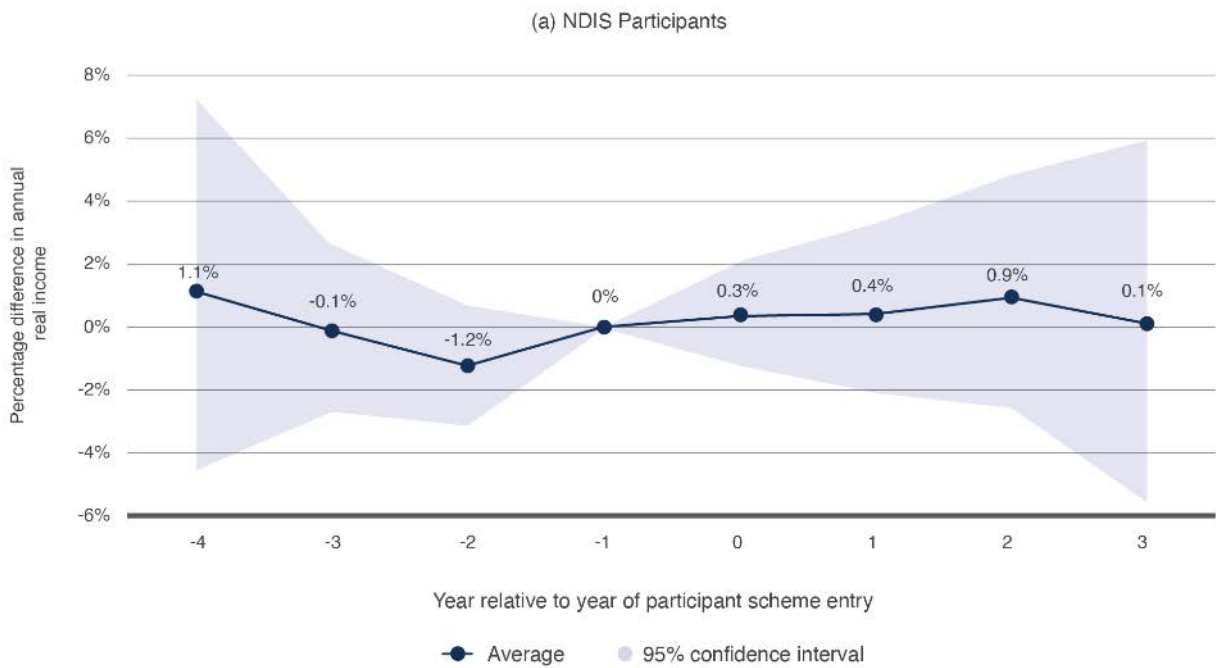
Women are likely to have lower incomes after a family member becomes an NDIS participant

Our analysis also found some evidence that women household family members of NDIS participants had lower incomes after a household member became a participant, with incomes about $1,400 lower on average in 2020-21 dollar terms. These results are relatively insignificant compared to the financial benefits households receive in the form of NDIS support. The results imply a small labour supply disincentive on average, especially given the average size of NDIS plans. However, given the size of NDIS plans and the complexities of the NDIS it is probably unsurprising that women have not re-joined the workforce as much as was expected a decade ago and so this points to the importance of our recommendations to simplify the NDIS and ensure all participants have a Navigator. Due to data limitations, we also view these results as likely understating potential benefits associated with household members moving from unemployment or from out of the labour force into employment. We would expect these benefits to grow if our report is implemented.

Figure C2: Proportional difference in real 2020-21 NDIS participant household member income relative to their year before entry[2912]

(a) Female Household Members

(b) Male Household Members
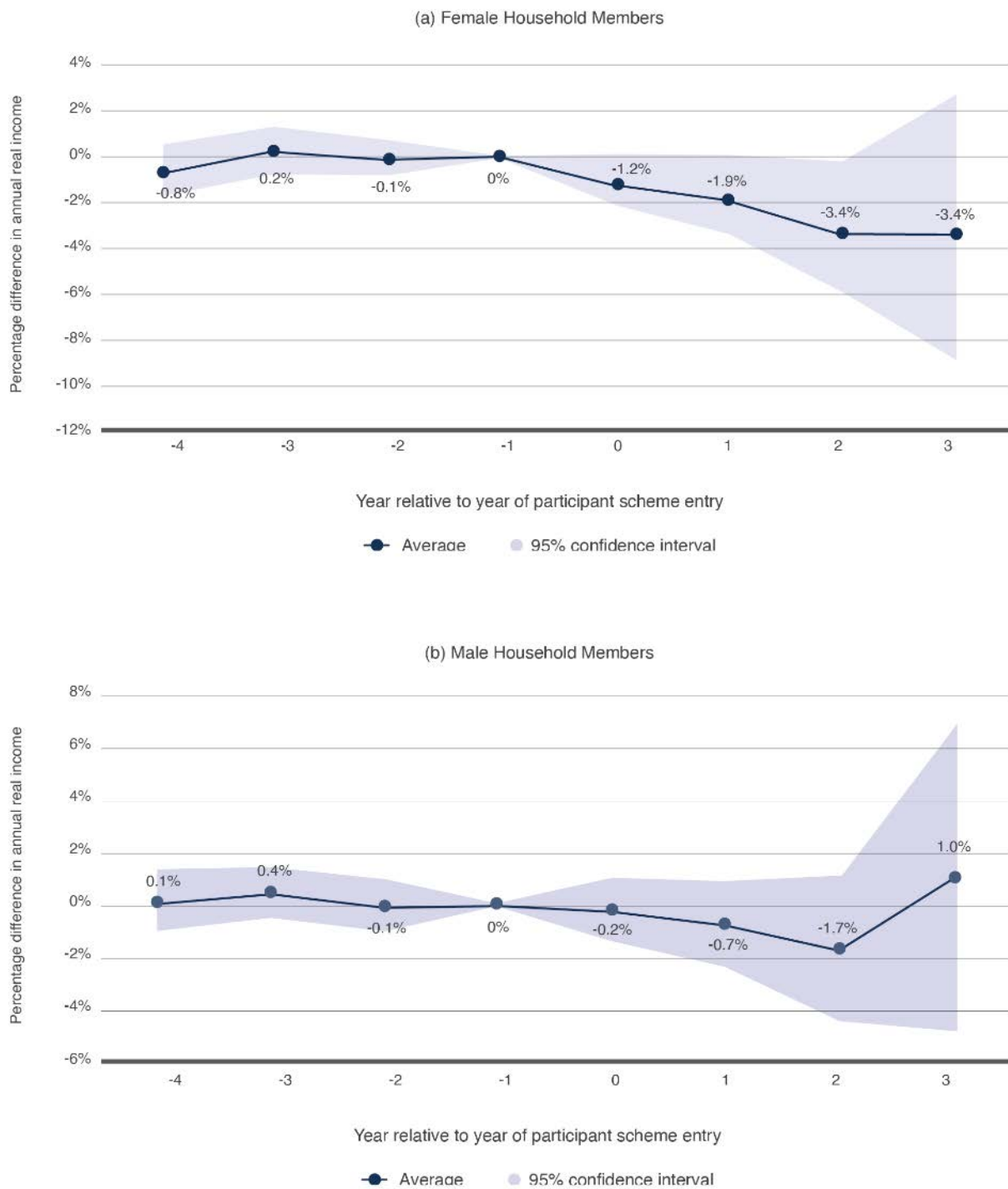
There is evidence the NDIS is contributing to better health and wellbeing outcomes for participants

Our analysis on the impact of the NDIS on Medicare benefits spending on in-hospital health care found some evidence the NDIS may have contributed to reduced hospitalisation levels for NDIS participants, and our analysis of Pharmaceutical Benefits Scheme (PBS) prescription data indicated reduced consumption of nervous system medications.

We found a relatively modest decline in participant related in-hospital Medicare expenditure of around 3.6 per cent relative- to pre-NDIS average spending, after a participant had been in the scheme for seven years (Figure C3). Using different techniques, estimated declines were also observed and showed larger declines in overall, in-hospital and non-hospital Medicare Benefits Schedule (MBS) spending, albeit with lower levels of statistical precision. For instance, we found some evidence of declines in overall MBS spending equivalent to around 18 per cent after six years in the scheme, albeit only statistically significant at the 10 per cent significance level.[2913]

Similarly, we observed a declining trend in the quantity of nervous system medications prescribed including antipsychotics and antidepressants post-NDIS entry, suggesting benefits in terms of reduced psychological distress, and improved participant wellbeing. These effects were relatively modest but important reflecting about 8.4 per cent lower consumption levels relative to the in-sample average over the entire 2017 to 2022 period (Figure C3).

Figure C3: Difference in NDIS participant (a) real 2022 in-hospital MBS benefits paid ($); and (b) annual quantity of PBS subsidised nervous system medications relative to year before entry[2914]

(a) In-hospital

(b) Nervous System Medications
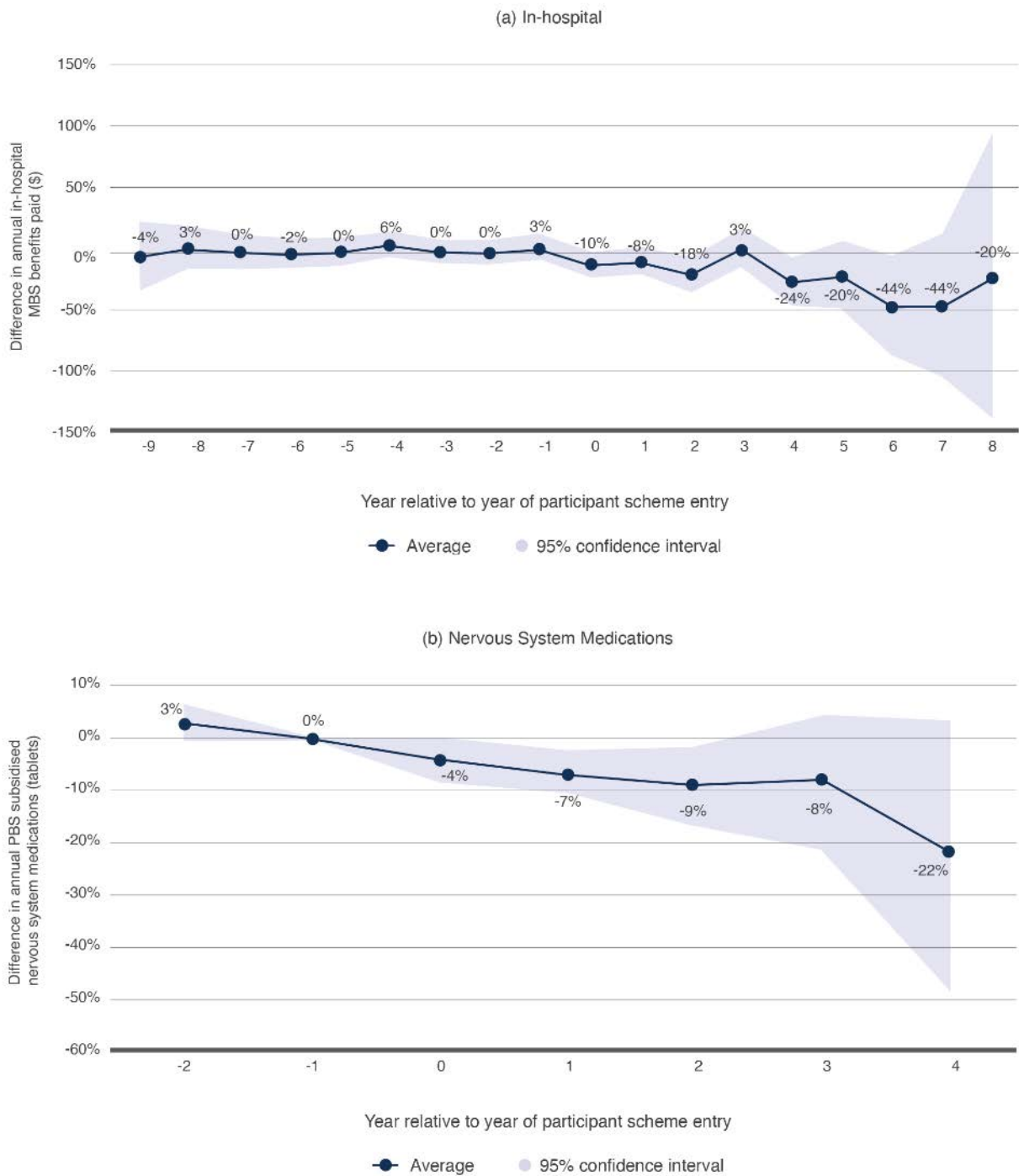
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[2912] NDIS Review analysis of MADIP utilising ATO Income and loss and NDIS participant data using the method of De Chaisemartin and D'Haultfoeuille (2022). Household members were linked to NDIS participants based on 2021 Census. Dependent variable is the log real income measured in constant 2020-21 terms, deflated using changes in aggregate average total income and loss per person data from the ATO income and loss data. Panel (a), n=2,022,210; panel (b), n=1,796,712). In both cases the joint placebo tests necessary for statistical identification are satisfied (p=0.38 and p = 0.85 respectively). Controls include participant and year fixed effects, participant-by-year fixed effects, household member age, household member age squared, and participant specific linear time trends. Standard errors are clustered at the participant level.

[2913] Estimates of NDIS participant MBS benefits paid after scheme entry in real 2022 dollar terms (joint placebo test for statistical identification p value=0.29, n= 7,289,820) based on the methods of De Chaisemartin and D'Haultfoeuille (2022). Controls include participant and year fixed effects, and participant-by-year fixed effects. Standard errors are clustered at the participant level.

[2914] NDIS Review analysis with Panel (a) estimates difference in NDIS participant in-hospital MBS benefits paid after scheme entry in real 2022 dollar terms (n=7,238,556) based on the approach of Callaway and Sant'Anna (2021). MBS spending is deflated using the Wage Cost Index 5 (WCI5) wage deflator sourced from the Department of Finance, the deflator used to index MBS spending. Panel (b) estimates effect on prescription quantities of PBS subsidised nervous system medications for NDIS participants after scheme entry based on the methodology of De Chaisemartin and D'Haultfoeuille (2022) (placebo estimate=2.60, n=3,646,902). Controls include participant and year fixed effects, and participant-by-year fixed effects. Standard errors are clustered at the participant level.