



## What we have heard

Moving from defining problems to  
designing solutions to build a better  
NDIS

June 2023



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# Part A - Overview

As you know, Disability Ministers have asked us to review the NDIS and, especially, improve the experience of participants and ensure that the NDIS is sustainable.

This report outlines what we have heard so far from you. Part A draws out five issues which we think are the most challenging and important given our Terms of Reference from Ministers and what you have told us. Part B provides more detail on 10 areas you have identified for improvement.

For each area, we have included questions. We invite you to answer the questions which are most important to you, because 10 years on we need all your collective wisdom and experience to help us find solutions to the key challenges facing the NDIS today.

## Ten years on

Ten years ago, people with disability, their families and the organisations supporting them came together to fight for the creation of the NDIS. It was a collective effort to change Australia for the better, underpinned by the UN Convention on the Rights of Person with Disability.

It has been an extraordinary journey since then. Australia has led the world.

You have told us the NDIS has transformed the lives of many people with disability and their families. You have told us about the difference NDIS supports make to your everyday lives and to your hopes and plans for the future.

We have heard how much you value choosing and organising supports in the way that works best for you. We have also heard about quality services and skilled workers who really care and want good outcomes for participants.

The NDIS continues to also generate significant broader social and economic benefits for Australia. Employment growth in the care and support sector is just one example of broader benefits.

Australians have told us how proud they are of the NDIS. They see it as practical expression of Australian values of fairness and opportunity.

## What we've learned so far

Ten years of experience with the NDIS also means ten years of learning that can be applied to making the scheme better.

Since we began our work many of you have shared your experiences in the NDIS. This is invaluable to our work – we can't do it without you. With a better understanding of what is causing problems, we can develop better solutions.

At the heart of our Terms of Reference is improving the participant experience.

You have told us how complex and costly the processes in the NDIS are. Navigating the system is leaving participants and their families exhausted and stressed. These issues touch every part of the scheme from when participants join the scheme and create their plans, through to getting supports and how they are delivered.

*"I love the NDIS. It has been a life saver for my family but not without stress, anxiety... and seeing my family at breaking point. Every year we go through the same mundane crap and have to fight the fight, not knowing what the outcome will be." – Family member or carer*

## **Five key challenges**

As we have reflected on all the things you have told us, including your experiences as participants and as families, five key issues have emerged. We would especially like your ideas about how best to solve these five major challenges.

### **Why is the NDIS an oasis in a desert?**

The NDIS was never designed to support all people with disability.

Community supports for all people with disability, as originally proposed, have not been delivered. As a result, the NDIS has become an oasis in the desert. This has had a significant impact on the cost of the scheme. It has also left people who are not in the NDIS without support. This is deeply unfair.

*We want your feedback on the best ways to overcome this failing. What supports from governments, business and the community are missing? Does the original vision need to be rethought because people with disability do not neatly fit into silos or 'tiers'?*

### **What does reasonable and necessary mean?**

The NDIS funds 'reasonable and necessary' supports for participants. But reasonable and necessary is poorly defined. This unresolved issue is the cause of many of the scheme's challenges – including stressful, time-consuming and poor planning experiences, inconsistent and inequitable decisions about funding and disputes between participants and the Agency.

*We want your feedback on how to best clarify and put into practice reasonable and necessary so that outcomes are clear for participants and everyone knows what to expect from the scheme. What frameworks or processes could help make this fundamental change?*

### **Why are there many more children in the NDIS than expected?**

Many more young children are entering the scheme than was expected. This partly reflects overall higher-than-previously identified rates of disability amongst young children. It also reflects a lack of supports for children with disability, outside the NDIS, in mainstream settings. With so few supports outside the NDIS, it is not surprising that parents are fighting to get their children with developmental concerns, delays and disabilities into the NDIS. Then, after receiving early intervention supports, they are not leaving the scheme. The Panel has found that early intervention is not always based on best practice. Support for families has largely been ignored. There has been a focus on diagnosis rather than support needs. These failings – together with the lack of supports for all children with disabilities in mainstream settings – is undermining the sustainability of the NDIS.

*We want your feedback on how support for all children with disability should be structured, not just those in the NDIS. What is the best way to support children with disability and families?*

### **Why aren't NDIS markets working?**

The markets in the NDIS have not worked as originally imagined. Competition has not produced improved quality, innovation or diversity of services for all participants in all locations. For many participants, especially in remote areas, the limited availability or poor quality of services means that in practice they do not really have choice or control over their supports.

Workforce quality, training, and retention are also major issues. The market system has not driven inclusion and helped to nurture connections with family, friends and community. In fact, sometimes the exact opposite has occurred. All of these failings are undermining outcomes for participants and contributing to increasing scheme costs.

In addition, not only do we not know whether participants are getting good outcomes such as employment and a good life; but we also don't know the relative quality of the supports they receive.

*We want your feedback on how, when and where NDIS markets could be better designed, structured and supported. What needs to be done to ensure NDIS markets serve the interests of people with disability, rather than the other way round? Where will markets not work? How can scheme help participants become more independent; not more dependent?*

## How do we ensure that the NDIS is sustainable?

The NDIS is an uncapped, needs-based scheme. However, the NDIS must also be sustainable and its costs predictable for governments and the public. It also must provide certainty for participants and their families.

*We want your feedback on how to best to measure both the benefits as well as the costs of the scheme and how to ensure the scheme is sustainable. How can the Review better balance the goals of choice and control and sustainability and contribute to the new sustainability framework foreshadowed by National Cabinet?*

## What's next?

We are now responding to the issues you have identified. We are looking for solutions. We are especially looking for solutions in the priority areas we have identified as the most challenging and needing the biggest shifts.

We need your help again. We need your insights to help to answer as many questions as you think are important to you.

We also would like you to tell us if we have missed anything important to you.

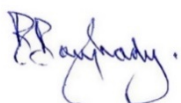
You can send us your ideas through our online survey at [www.ndisreview.gov.au](http://www.ndisreview.gov.au) as well as in-person and online engagement opportunities through the Review, disability representative organisations partners.

The same collective effort from ten years ago is required again today. Together, we can get the scheme we fought for back on track.

Our recommendations in the final report will go to disability ministers in October 2023.

Between now and then we look forward to engaging further with you as, together, we find solutions we can present to governments.

Yours sincerely



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# Part B – Priority areas for improvement

## 1. Applying and getting a plan

You have told us that getting access to the NDIS is not simple or straightforward. Once in, planning processes are complex, confusing and stressful, there are problems with the culture of the NDIA and that there is little trust or confidence in decisions.

### What you told us is not working

From what you told us we understand:

- Applying for the scheme is confusing and difficult. It is not clear what evidence is needed or who should provide it. The criteria around meeting the significant impairment requirements are unclear. Access to the scheme has become focused on diagnosis rather than need.
- The planning process is focused on what people can't do, instead of what they can. Participants and families feel pressure to present the worst versions of themselves or their children to make the case for support. This is stressful and traumatising.
- Participants often feel judged by those they do meet in the planning phase. They don't feel believed when they try to describe their needs and circumstances.
- Given this lack of trust, planning meetings can become arguments about whether individual supports should be included in a plan, rather than a chance to actually plan effectively for the present and the future.
- The adversarial nature of planning has created an unhelpful cycle. When people feel they are not trusted, it makes it hard for them to trust support will be there for them if their circumstances or needs change.
- For some, this process and experience is so traumatic they are unwilling to deal with the NDIA. This is particularly true for those that have intersecting identities or multiple forms of disadvantage.
- Participants are not recognised or respected as experts in their own life. The focus on using professional reports as evidence is not fair, creates a huge administrative burden and is expensive for people applying. These reports often assess people with disability outside the places where they usually live, play, learn or work - and miss essential information. It is unclear how the reports are used.
- Most participants never meet the person who will make decisions about their plan and budget – which is their future. Participants often feel that the people who help with the planning phase do not understand their disability, or the complexity of their lives.
- The majority of participants have a cognitive disability and so the processes for applying and getting a plan need to better recognise the needs of this group.

- For First Nations Australians and those from culturally or linguistically diverse backgrounds, NDIS processes must be culturally safe and trauma informed.
- Some groups in the disability community aren't aware of the NDIS or that they can apply for support.

### **What this means for participants**

People with disability find applying for access to the scheme very difficult. Planning processes are complex and confusing. This is true for all participants, but it has a particular impact on participants and families who have multiple forms of disadvantage. This means people with the greatest need often get very poor outcomes.

Most participants feel they don't have a person in the NDIA who understands them or their needs. They have to prove their disability and their needs over and over again. Decisions are made for them rather than with them or by them. Participants don't understand how decisions are made or why. There is no trust or certainty.

*"To have to talk to someone, with no understanding, no empathy or any idea of what it's like to live like this, and these people are deciding what I can and can't have, what's reasonable and necessary when they have no experience or understanding is a complete recipe for disaster" – Participant*

*"I have found the whole process stressful and defeating." – Participant*

*"[There is] no continuity within the NDIS, you get a different person every time and they request something different every time." – Family member or carer*

### **What we want to know now**

How can we empower you through the planning process?

Prompts to help you answer this question:

- What does the NDIA need to know about you to make better decisions on whether you are eligible for the scheme?
- What would make access and planning simpler and less stressful?
- How can the NDIA engage better with First Nations Australians, people from culturally or linguistically diverse backgrounds, people who identify as LGBTIQ+, gender diverse people, people with complex needs and people from disadvantaged backgrounds in the planning process?



## 2. A complete and joined up ecosystem of support

We have observed that support for Australians with disability is not planned, funded or governed as a whole ecosystem. There is not enough support for people with disability outside the NDIS. This is unfair and is undermining the sustainability of the NDIS. Which results in people falling through the cracks and missing out on much needed support.

### What you told us is not working

From what you told us we understand:

- The NDIS is supposed to be one part of an ecosystem that provides disability supports. The ecosystem was meant to:
  - o Promote opportunities for people with disability, and create awareness of the issues affecting people with disability and the advantages of inclusion.
  - o Inform on effective care and support options, and make referrals to relevant community and mainstream services for a range of community and carer support services for people with lower level or shorter term disabilities.
  - o Fund individualised supports.
- The ecosystem isn't working as intended. All governments have significantly increased funding for disability services in the last decade – from \$8.2 billion in 2012-13 to \$31.3 billion in 2021-22. Almost all of this funding has gone to disability funding through the NDIS. In 2021-22, supports within the NDIS made up more than 93% of all disability funding.
- There is a growing gap between the types of supports available inside and outside of the NDIS. Both adults and children with disability who do not receive funding from the NDIS miss out on the supports they need. This is deeply inequitable.
- Government services for people with disability are not working together. Services and supports are split between multiple levels of government – federal, state or territory and local. They are also divided up into different systems, departments and agencies.
- These disconnected systems are hard to navigate and there are gaps, which means people with disability can't get the supports or assistance they need.
- More time is spent arguing about who is responsible for what, and who should pay for it, than on making the ecosystem work.
- The Information, Linkages and Capacity Building program is a short-term grants program and has not provided sufficient investment to match its ambition of delivering projects that benefit all Australians with disability, their families and carers.
- Local area coordinators and early childhood partners have not been able to support people with disability outside the NDIS or deliver community capacity building and link people to services or community activities as intended.

- Supports for people who aren't eligible for NDIS, such as Home and Community Care programs and psychosocial support services, are provided insufficiently and inconsistently across jurisdictions and geographies.
- There are not enough supports for children outside the NDIS despite growing demand.
- There has not been enough attention or action in making mainstream services or community programs, services or activities more inclusive and accessible.
- The Australian Disability Strategy needs to be adequately resourced.

### **What this means for participants**

Too much time is spent navigating the ecosystem to find out where to get supports. Participants apply for and stay in the NDIS for fear of a lack of support outside of it. And people who cannot access the scheme are missing out on vital supports and services, increasing future needs. This puts great financial stress on the scheme.

*"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." – Organisation*

*"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." – Organisation*

*"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." – Family member or carer*

## **What we want to know now**

What is the best way to provide supports for those not in the NDIS?

Prompts to help you answer this question:

- What services and supports should be available to people with disability outside the NDIS and who should provide them?
- How can governments work better to deliver a joined up system of inclusion and support for all Australians with disabilities (within and outside the NDIS)?
- Should some supports be available to all people with disability and so both in and out of the NDIS?

### 3. Defining reasonable and necessary

Lack of a clear, shared understanding of what is considered 'reasonable and necessary' leads to complexity, confusion, conflict and inconsistency.

#### What you told us is not working

From what you told us we understand:

- Participants are confused about what the NDIA considers reasonable and necessary. They are also frustrated by inequitable funding decisions based on this concept.
- While the criteria for reasonable and necessary have deliberately been kept broad to make sure support can be tailored to the individual, it has made it difficult for NDIA decision makers to make consistent decisions.
- Being fair and consistent is particularly challenging in a large scheme with participants who have a wide variety of disability types, co-occurring conditions and many experience intersectionality and then which needs to assess individual circumstances.
- It is not clear to participants how plans are assessed, how funding is calculated and what exactly it can be used for once it is allocated.
- It is not clear to participants how 'Typical Support Packages' have been put together or how they have been used.
- There is insufficient guidance for health professionals assessing support needs. This means they don't know what they need to include in reports to ensure people get the support they need.
- It is unclear to participants why advice from health professionals is not always supported by NDIA decision makers.
- Most Administrative Appeals Tribunal appeals relate to disagreements about reasonable and necessary

#### What this means for participants

Participants don't understand what reasonable and necessary means or how the NDIA applies it when making decisions. They don't know what evidence to provide to show their supports are reasonable and necessary, or how it will be used.

Without a shared understanding of reasonable and necessary, it is impossible for participants to know what supports to expect from the scheme or to have a planning process which is not stressful and confrontational.

*“Arbitrary rules - what is reasonable and necessary to me is not the same as it is to my planner... Being told a service is not reasonable and necessary by your planner but knowing someone (whom is in the exact same situation) else's planner has approved it.” – Participant*

*“What I see is a necessary item and helps me significantly (plus supported by allied health), the NDIS doesn't. Having the flexibility to understand what is important to a person in their life.” – Participant*

*“The onus must be reversed so that planners must prove why their decisions of what is reasonable and necessary disagrees with that of a qualified professional.”  
– Participant*

## **What we want to know now**

How would you define reasonable and necessary, and put it into practice?

Prompts to help you answer this question:

- How can reasonable and necessary be more clearly defined so that there is a shared understanding between participants and the Agency and participants have certainty about future funding?
- What would help you understand how reasonable and necessary applies to you?
- What steps could the NDIA take to make decisions about reasonable and necessary which are more consistent and fair?

## 4. Early childhood supports

Early intervention for children is frequently not based on best practice. Not enough support is built around families and helping children to be included in their local community.

### What you told us is not working

From what you told us we understand:

- The needs of children and families are not being considered holistically. There is a lack of family-centred practice. As a result, families don't feel supported.
- Parents feel the focus is on "parental responsibility" rather than working out how to get the best outcome for children.
- There is not enough focus on supporting children and families in their everyday environments – in the home, in early childhood education and services, and in the community. The increasing reliance on therapy delivered in clinical settings has got in the way of children living ordinary and inclusive childhoods.
- There are few incentives and no mechanisms to make sure early intervention providers deliver evidence-based supports or adopt best practice when supporting children and their families.
- Families want better information and advice to help them make decisions about which supports and services will help their child.
- There is constant pressure on the NDIS to meet the needs of all children with developmental concerns, developmental delay and disability because other service systems or other community supports are not available or accessible.
- The education system needs to be much more inclusive of all children with disability and support them much better so that they can reach their potential.
- Children with disability are also not being identified early enough in life. This is particularly true in remote communities where the average age of children entering the scheme is higher than that in cities and regional areas. Children in remote areas are also less likely to be accessing the scheme.

#### What this means for participants

Parents and families feel they don't receive the right supports from the scheme. They need more information and more support to find services which are based on the most up-to-date and comprehensive research, and which will help their child to thrive and be included in all aspects of home and community life.

*"[I] shouldn't have to dream up a goal to justify a thing that NDIS knows is best practice for your child. Should be information about what a typical support plan looks like, you should ask for these things. If you don't know about it, you don't get it."*

*– Parent*

*"Clear pathways and information to new parents, with an understanding that for parents they are brand new to the world of disability." – Parent*

*"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" – Parent*

## **What we want to know now**

What is the best way to support children with disability and those with emerging developmental concerns?

Prompts to help you answer this question:

- How can supports for children with disability be delivered in ways that lead to better outcomes for children?
- What does good support look like for children living with disability?
- In what settings should that support be provided, and by who?
- What supports or services do families need to help their children with disability thrive?
- How should families with children with disability be assisted and supported to navigate early childhood services?
- What supports for children with disability should be available outside the scheme?

## 5. The support and service marketplace

NDIS 'markets' are not yet working for all participants. The current approach to the market relies too much on competition. Not all participants have access to the supports they need.

### What you told us is not working

From what you told us we understand:

- There is not just one market in the NDIS, there's many sub-markets in many locations.
- Participants find it hard to search for good services and connect with providers.
- Providers find it hard to respond to what participants need.
- Governments don't have the information they need and don't know if the supports being provided are working to help participants to reach their goals.
- In some places the number of providers or participants in the NDIS is too small for a market to work well or at all. This ends up in what we call a 'thin market'.
- Gaps in delivery are particularly evident for First Nations and remote communities who are being left behind under a rigid market approach. Too many participants who live in a remote community are not getting daily activity supports, or the therapy services they need. The NDIS should align with Closing the Gap.
- The main way the market is currently managed is, by setting rules around how much and the way providers are paid. This includes 'price caps' which are set by the NDIA to say the maximum amount a provider can charge a participant.
- Price caps aim to ensure providers do not drive up prices and that their services are value for money. However, the blunt and non-transparent way price caps are set is not helping providers respond to the needs of participants or encouraging innovation. We've heard from some providers this also makes it hard to invest in the capability of workers. It is also fuelling a fee-for-service mentality amongst providers.
- While price caps are slightly higher for participants with complex needs, past reviews have heard that the current price caps don't do a good job at supporting access for participants with complex needs.
- We know that providers often charge participants at the maximum price. In the NDIA's 2020-21 Financial Benchmarking Survey, over four in five providers (83%) reported always setting prices at the price cap. We also know participants may not change their provider when prices change, so there is little reason for providers to compete by lowering their prices or improving the quality of supports.
- As the NDIS grows, more workers are needed to support people with disability. Both service providers and participants report that it is hard to find and keep workers with the right skills, values and attitudes, especially for complex clients and in remote areas. Jobs can be short term with poor conditions and many workers aren't staying.

- Many of the challenges facing NDIS workers are similar for workers in aged care and veterans' care, and some people work across the care and support sector.
- Coordinated action is needed across the care support sector. Making care and support work more attractive, as well as making it easier for workers to move across the sector may open up more career options and encourage people to join and stay.

### **What this means for participants**

It can be hard for participants to find the right services that meet their needs close to where they live. They also find it hard to find good support workers with the right skills, values and attitudes. They want more support to help them find and choose services, and to recognise what a good service looks like.

*“Regional and remote areas have limited supports, limited safeguards and poorer quality supports. Market based systems do not work in thin markets. People with disability in regional and remote areas are afraid to complain about the few supports they have in case they are withdrawn” – Organisation*

*“Workforce shortages are real and impacting the sector across the board. It reduces the capacity of support providers to provide consistent and reliable supports.”  
– Provider*

*“Despite living in an area of 'on paper' good service provision... accessing services for my daughter has been difficult - many providers have 'closed books', or have such limited availability as to not be a viable option... Limited providers also mean sticking with a 'known' provider even if you aren't satisfied with the service, for a lack of alternative options.” – Family member or carer*

## **What we want to know now**

How can the markets be better designed, structured and supported?

Prompts to help you answer this question:

- What needs to be done to ensure the markets serve the interests of people with disability, rather than the other way round?
- What options would help when supports and services are not available in your region?
- What information do you need to understand what good service looks like?
- How could the pricing structure be redesigned to reward outcomes rather than the volume of transactions?



- What would attract and keep workers who have the right skills, value and attitudes?

## 6. Measuring outcomes and performance

Better measurement of outcomes and performance would help participants make informed choices, keep providers and government accountable, and make sure the scheme is sustainable. It would also help the NDIS improve over time.

### What you told us is not working

From what you told us we understand:

- The performance of providers and services is not measured or rated.
- Participants don't have enough information to make informed choices about whether a service will meet their needs or deliver a good outcome.
- Providers aren't incentivised to support participants achieve good outcomes and are not rewarded for providing good or great services, or pulled up when they are not performing as they should.
- High quality supports and outcomes are not the same for all participants. For some it is getting a job, while for others it's improved community participation and quality of life.
- While the NDIA has some outcome measures, understanding where the NDIS is working well and where it needs improvement is still very difficult to see. Better measurement of performance of the scheme would help ensure it improves over time.
- More effort on measuring individual and NDIS level outcomes would help everyone understand the impact of the scheme on individuals, the community and the economy. It would help governments understand the impact and return on the funding they are investing.

#### What this means for participants

The lack of data and evidence means there is little information for participants to help them choose services. It also means providers and governments are not being held accountable for outcomes.

*"The scheme does not have a mechanism to assess the extent to which participants achieve their individual goals, or the impact of funded supports on goal achievement and outcomes, to inform future planning decisions. There is limited understanding of what types of supports lead to good outcomes, and thus the outcome data in current form may be of limited use to actuaries in informing future estimates of scheme expenditure. Outcomes data is of variable quality and reliability... associated with the*

*experience and expertise of the planner in administering such surveys, the time available to complete... and the extent to which the participant understands the questions.” – Provider*

## **What we want to know now**

How should outcomes and performance be measured and shared?

Prompts to help you answer this question:

- How should you, your providers and the NDIA keep track of how your supports help you achieve goals or outcomes?
- How should governments and agencies be monitored to make sure they do what they say they will to support you? Who should perform this monitoring role?
- How should we measure the impact and benefits of the NDIS for the broader Australian community and the economy? How should this information be shared?
- How can we build a system where the NDIS keeps improving based on evidence?

## 7. Achieving long term outcomes

We have observed that there is a lack of focus on achieving long term outcomes relating to participation, inclusion in communities and employment. A good life is one enriched by connections to family, friends and community. These need to be nurtured by the scheme.

### What you told us is not working

From what you told us we understand:

- The planning process is more focused on immediate needs rather than achieving long term outcomes contributing to a good life. There is not enough consideration of what it takes and how long it takes to build a good life.
- Information about the best ways to achieve good outcomes or what good services look like is not always available to people with disability and their families. This means providers are not encouraged or supported to deliver better outcomes or try new things. Even when good or innovative services exist, it's hard for participants and their families to find them.
- NDIA planners and decision makers, local area coordinators, early childhood partners and support coordinators need better information about best practice or what supports are more likely to deliver good outcomes. They would then be able to encourage the use of evidence-based supports.
- Families of children need more information about family-centred and multi-disciplinary services that can deliver better more inclusive outcomes for children, compared to solely receiving therapy delivered in clinical settings.
- For participants with a psychosocial disability, the lack of a specialist planning pathway with a focus on recovery has contributed to reliance on core support. This has come at the expense of capacity building to enable recovery and improve social and economic outcomes.
- The scheme is intended to help people become more independent, more included in their community and live an ordinary life. But for many, connections to family, friends and community have not been nurtured by the NDIS, resulting in an over-reliance on paid services and increased segregation and vulnerability.

#### What this means for participants

Without good information and support, it is hard for participants to find and choose supports that will meet their needs and help them achieve their goals.

*“Recognise that there are structural discrimination and barriers for disabled people to access ‘normal’ society and earn the ‘normal income’ which facilitates that. Allow people with disability... to use their funding to access ‘normal’ social activities to help overcome this structural barrier to achieve their goals, especially for children and young people... These things improve mental health, along with social participation.”*  
– Person with disability

*“My kids miss out on social/community participation opportunities with kids like them and instead spend huge amounts of their free time and school time doing draining one on one therapy with the clinic's that we can get a spot in - where the practices are not necessarily neuro-affirming.”* – Carer

## **What we want to know now**

How would you like to build better outcomes into your plans?

Prompts to help you answer this question:

- How can the scheme build goals that nurture connections to local community?
- How can you use your funding to help you connect with friends and family, learn new skills or try new things? What is keeping you from doing that now?
- How can you use your funding to help you prepare for, join, or stay in employment? What needs to changes to make this work better?

## 8. Help accessing supports

The roles of 'intermediaries' such as local area coordinators, early childhood partners, remote community connectors, support coordinators and plan managers overlap, leave gaps and are confusing.

### What you told us is not working

From what you told us we understand:

- Participants and their families do not have the support and information they need to help them find providers, compare what they are offering and make an informed choice about what will work best for them. It can be hard to find someone they can trust to provide advice, information and advocate for them.
- There are lots of intermediaries who are meant to help participants find and use services. They include local area coordinators, early childhood partners, support coordinators, remote community connectors and plan managers.
- Intermediaries spend too much time and money trying to work through NDIS processes because the scheme is overly complex and changing constantly. This takes away from their time helping participants to connect into their local communities, get good outcomes and make most of the funding they receive.
- Without clear roles or expectations about what 'good supports' look like, many participants don't know who they should be working with to make decisions about supports and services. This is particularly difficult for participants who experience multiple disadvantages.
- There are significant additional challenges for those participants with complex needs who need to navigate multiple systems and for whom siloed service delivery models create confusion and frustration because they do not put the person at the centre.

#### What this means for participants

It is not clear to participants who should be helping them navigate the scheme and when. Rather than being helpful, for many working with intermediaries has become just another frustration.

*"No one informs you what things are, they just expect you to know, they just expect you to know how plan management works and what a plan manager is and what they do." – Participant*

*“There is no consistency and I get a different answer every time I ask a different person. Your [local area coordinators] are not trained properly... The NDIS is so overly complicated that I need to pay a plan manager (way too expensive) and a support coordinator (also expensive) to help me navigate.” – Family member or carer*

*“... [Local area coordinators] do not seem to have the time, inclination or skill to support people to build capacity to understand their NDIS plans, the scheme, how to work with providers (safeguarding). It is not unusual for a participant or nominee without support coordination funding to come to me for plan management services halfway through their plan, having not engaged with anyone, because they have no idea what to do, or where to go, and have not received any support from the [local area coordinators] or [early childhood early intervention] coordinator.” – Provider*

## **What we want to know now**

What does good service from someone helping you navigate the NDIS look like?

Prompts to help you answer this question:

- What skills and knowledge do you need from someone who helps you navigate the system?
- What (people, systems or processes) would make it easier for you to make informed choices, manage your funding and pay your providers?
- What would make it easier to understand how your funding should or should not be used?
- How should service navigation be structured for those who need to access multiple service systems so that they work together?

## 9. Supported living and housing

Many participants with housing and living supports in their plans still have limited choice in where, how or with whom they live. There has been little innovation in housing and living supports. The supply of specialist disability accommodation is not always meeting the needs of participants.

### What you told us is not working

From what you told us we understand:

- Achieving better housing and living outcomes is critical to the scheme delivering greater inclusion for people with disability and connection to family, friends and community.
- However, planning decisions often don't consider housing and living supports in a holistic and connected way. Decisions are often not transparent and inconsistent, and there is not enough support for participants to explore their housing and living needs options and arrange their supports.
- Contemporary housing and support models have been slow to develop.
- Supported Independent Living and outdated 'group houses', where participants are not actively supported in community life and where there is significant risk of harm and abuse, still dominate the system.
- There is not enough innovation. Individualised Living Options, which were very creative and flourished in WA before the NDIS, are shrinking.
- There is too much large, old and poorly designed specialist disability accommodation. There has been insufficient market facilitation to incentivise redevelopment and meet the expectations of residents.
- The supply of new accommodation is not sufficiently responsive to demand or being built in the right locations.
- There are many perverse incentives affecting housing and living arrangements and incentives are not aligned to good outcomes for participants or a sustainable NDIS.
- Too few housing and living arrangements are fostering more inclusive and connected lives in community.
- More individualised housing and living settings can have significant cost and workforce implications if there is not enough planning and investment in informal support, assistive technology and capacity building.
- There have been numerous calls to reconsider the regulation of group home settings to ensure the safety of participants and the quality of supports they receive.
- More broadly outside the NDIS, there is a lack of accessible and affordable housing in Australia. This has a disproportionate impact on people with disability, particularly

those with high support needs, who are more likely to have fixed or low incomes and more likely to need accessible housing.

- There is not enough focus on how housing and living decisions should be both underpinning good outcomes for participants and consistent with a sustainable NDIS.

### **What this means for participants**

Participants do not know how housing and living options align with reasonable and necessary supports. They are also not able to exercise enough choice and control over their living situation. Too often they are unable to find the housing and living supports they need, or the right people to help them to make decisions about where to live and how to arrange their support.

*“We [have] little to no say in our housing - providers are building whatever, without co-design.” – Participant*

*“A participant applying for [specialised disability accommodation] faces extreme stress, to the point of psychological distress. It is without a doubt the worst process I've ever had to go through.” – Participant*

*“[Supported independent living] is often the only option given to a person with high support needs, so no real choice. The [supported independent living] funding rarely allows for anything other than congregate living arrangements and does not take into account the relevant research in relation to the impacts of this model.” – Advocacy organisation*

### **What we want to know now**

How should housing and living options be improved to build a good life?

Prompts to help you answer this question:

- What would help you to make decisions about where, how and with whom you live?
- What are the features of living with people or living on your own that are important to you?
- What information, services or support do you need to feel safe and well supported in your home?
- How should the NDIA make decisions about reasonable and necessary housing and living supports, so that decisions are fair and much less stressful?



- How can housing and living supply responses be encouraged to be more innovative and aligned with participant needs?

## 10. Participant safeguards

The NDIS has not worked well enough to safeguard all participants, while making sure they can still have choice and control. More must be done to empower and build the capacity of participants to help keep themselves safe, and ensure systems are working together to improve safety and outcomes.

### What you told us is not working

From what you told us we understand:

- The NDIS has not done enough to build the capacity of participants and strengthen their natural safeguards so they can get the support they need, be safe, and manage the risks they face.
- Natural safeguards include being part of a family, having friends, being part of a community, understanding your rights and having support to speak up when something is wrong.
- It is challenging to balance ensuring participants can exercise choice and control, recognise the importance of dignity of risk, while also having the right regulations in place to keep people safe.
- Regulatory arrangements for providers and workers have not responded to changes in the NDIS and the market, such as new types of supports available to participants, and more participants self-managing their funding and using unregistered providers.
- Some unregistered providers are providing high quality and very innovative supports.
- Participants, providers and workers feel regulation is more about ticking boxes than improving the quality of services.
- More can be done to build the capacity of participants to keep themselves safe, manage the risks they face and get the supports they need.
- More needs to be done to reduce and eliminate the use of restrictive practices that limit participants' freedom of movement and their rights.
- Information sharing between government agencies needs to be more timely and effective to prevent harm and support people to be safe.

#### What this means for participants

Participants do not always get the support and safeguards that they need in a way that works for their own circumstances.

*“Participants also need to be given information about their rights from their provider whether registered or unregistered.” – Participant*

*“We have been through registered agencies, and they have been really bad for us... Sometimes [support workers] come in from the agency and they don’t know how to change a diaper, or how to care for someone having a seizure; they are basic things that I would expect someone coming from an agency to know.” – Parent of an NDIS participant*

*“My experience with [that support] made me feel very exploited.” – Participant*

## **What we want to know now**

How should the safeguarding system be improved for a better NDIS?

Prompts to help you answer this question:

- How can the regulation of providers and workers be used to improve the quality of services and supports?
- How can the NDIS build your capacity and natural safeguards to support you to be safe and get good outcomes?
- What should the NDIS do to get the right balance between your choice and control, the dignity of risk, and supporting you to be safe?
- How can all levels of government work together to prevent harm and promote quality in the supports you receive?
- What can be done to make progress in reducing and eliminating practices that restrict your rights or freedom of movement?