

# **Response to NDIS Review: What We Have Heard Report**



**Down Syndrome**  
Australia

## CONTENTS

About Down Syndrome Australia .....	3
Introduction .....	4
Applying and getting a plan.....	5
A complete and joined up ecosystem of support .....	7
Defining reasonable and necessary .....	10
Early childhood supports .....	12
The support and service marketplace .....	15
Measuring outcomes and performance .....	16
Achieving long term outcomes.....	19
Help accessing supports.....	21
Supported living and housing.....	21
Participant safeguards.....	24

## About Down Syndrome Australia

Down Syndrome Australia is the National peak organisation for people living with Down syndrome and their families. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion. People with Down syndrome are at the centre of all the work that we do. All our work is informed by the United Nations Convention on the Rights of Persons with Disabilities.

Down Syndrome Australia and its member State and Territory Down syndrome organisations work together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome. We work in partnership to maximise the opportunities and support for people with Down syndrome and their families and support networks.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 13,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.<sup>1</sup>

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<sup>1</sup> Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from <https://www.downsyndrome.org.au/about-down-syndrome/statistics/>

## Introduction

Down Syndrome Australia (DSA) welcomes the opportunity to provide input into the Independent Review of the National Disability Insurance Scheme.

We have consulted with our State and Territory Members, as well as our Down Syndrome Advisory Network on this submission.

Down Syndrome Australia's vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion. In line with the Convention on the Rights of Persons with Disabilities (CRPD) and Australia's Disability Strategy (the Strategy) we work towards a community where all people with disability are included, and their rights respected and protected.

DSA acknowledges the National Disability Insurance Scheme (NDIS) provides a range of supports that promote inclusion of people with disability in Australia. DSA applauds the National Disability Insurance Agency (NDIA) and the Australian Government for the Independent Review of the National Disability Insurance Scheme to ensure a more positive and productive NDIS and a more inclusive society for all.

DSA concurs with the approach taken by the Review Panel of putting people with disability at the centre of the NDIS, and restoring trust and confidence in the NDIS. **Trust and confidence in the NDIS are critical for the success of the scheme and the Review Panel is encouraged not to underestimate the importance of this for the implementation of reforms that come out of the Review.** Even the best reforms will fail if they are not delivered in a way which builds trust and confidence in the system. In our view, **the best way to build this trust and confidence is to implement reforms in a genuine co-design process of collaboration and consultation with the disability sector and participants.**

DSA has been actively involved in a number of areas of the NDIS Review. This report focuses on responses to the "What We Have Heard Report" but we encourage the Review Panel to consider these responses alongside our submissions, reporting and input in relation to:

- Home and Living Co-Design group.
- NDIS Information Gathering for Access and Planning Summary Report.
- Protecting our NDIS: Understanding of fraud and payment non-compliance among people with an intellectual disability and their families.
- NDIS Review: Submission on ILC.
- NDIS Review: Solutions for Planning and Transitions.

Throughout this report we have endeavoured to outline to the Review Panel the principles and key considerations in each of the areas of the report, which we hope provide context for the recommendations.

DSA would be happy to be engaged on the content of this report if the Panel has any questions or requires further information.

## Applying and getting a plan

### Key principles / recommendations:

- Simplify access for people with Down syndrome to the full scheme.
- Adopt a strengths-based approach to planning.
- Reinstate trust in the system by demonstrating consistency of process.
- Embed choice and control (including supported decision making) in the planning process.
- Present plans in an accessible format for people with intellectual disability.
- Split the roles within the Planning process between budget setting and support in utilising the plan.
- Train specialist planners by disability, transition area (e.g., Early Intervention to full scheme, school leaver, moving out of home etc), and intersectionality.
- Supported decision making needs to be incorporated into all aspects of plan implementation and should be funded in participants plans.

### Access

Children with Down syndrome should enter the NDIS soon after birth. Down syndrome is on *List D Permanent Impairment/Early Intervention*. DSA is aware of situations where planners have told parents to “wait until there is a developmental delay” until they access the scheme. This is not the best early intervention approach and should not be occurring. The Review states that *“The NDIS takes a lifetime approach to achieving these outcomes, investing in people with a disability early to improve outcomes later in life and improve system sustainability.”* The early investment is critical in the case of Down syndrome as the condition is generally diagnosed before or very shortly after birth, giving the maximum opportunity to invest early.

When entering the full scheme (at age 9 or above), Down syndrome is on List B: *Conditions that are likely to result in a permanent impairment - chromosomal abnormality resulting in permanent impairment* and therefore are not automatically eligible.

DSA understands that over 95% of people with Down syndrome applying for access to the full scheme get access (and the number could be even higher on review of these access decisions).

DSA recommends that Down syndrome is added to List A for automatic eligibility to the scheme. This would save significant cost and administrative burdens on both the NDIA system and on participants applying for entry, without having a significant impact on scheme costs.

### Planning

Planning meetings and the planning process needs to be more accessible and inclusive of people with Down syndrome and other intellectual disability.

Supported decision making needs to be embedded in the planning process, and DSA would like to see planners specifically trained in supported decision making, intellectual disability and accessible communication (see below “Specialist Planners”). People have the right to be involved in their planning meetings and process. It provides opportunity to build self-advocacy and decision-making capacity and for people to have real choice and control.

*“This will make people feel heard and supported rather than like they are going into battle.”*  
Parent

Planning could be made simpler and more transparent by relying less on evidence of disability, and therefore a Typical Support Plan, and more on the functional capacity of the participant to achieve their goals, and their support needs. Planning needs to move from a deficit-based approach to a strength-based approach that looks at people's needs to achieve goals and social and economic participation. This could be achieved by the questions that are asked, and who evidence is obtained from. In particular the perception that Participants and their healthcare professionals' views and opinions are prioritised below the Planners "opinions" needs to be addressed. Addressing this perception will build trust and confidence in the NDIS amongst participants and their supports.

*"It is very important for me to be involved in something like this because I want ownership of my life and I also want my voice to be heard."*

Participant

Transparency of decision making, and improved consistency of decision making is needed. Importantly, DSA would like to note that it is not necessarily consistency of outcomes that is required, as all participants are individuals with their own circumstances and support needs. What is required is consistency of process applied in arriving at those decisions so that any differences in support needs (and therefore budget) can be explained by differing individual circumstances rather than by a different application of process or rules.

In particular, the concept of people who can afford the expensive therapist reports get the best support plan needs to be addressed. Therapists reports are only part of the equation and evidence of therapy and support needs can be obtained in other more equitable ways.

*"Transparency of decisions is so important, and this is why people are often left feeling they have not been treated fairly by the NDIS as they compare their situation to their friend or peer and then compare the funding and do not understand the inconsistency across various planning decisions. Through transparency of decisions, people will become more educated on why they have received different funding to their peers and friends."*

Down Syndrome State organisation staff member.

Transparency of planning decisions could also be improved by Participants and/or parents or carers being able to review and provide feedback on a draft Plan.

*"Giving people the opportunity to discuss a draft plan gives them a feeling of being empowered and have more opportunity to discuss and therefore understand planning decisions."*

Parent

Planners also need more time to develop a plan that is tailored to each individual's needs. There cannot be a cookie cutter approach to plan development, allocating the same amount of time to each individual. The NDIA should consider other metrics on the success of the Planner rather than number of plans developed. These metrics could include: extent of reviews of plans developed, co-design of the plan by participants and their supports, satisfaction of the participant in those plans, achievement of participant goals outlined in the plan. The high work loads of LACs and Planners, and dissatisfaction in being able to support people well has led to some quality staff leaving these roles. Retaining staff will lead to better outcomes for participants who have developed a relationship with their planner over multiple plans. This continuity of care will continue to build trust and confidence in the NDIS for both the participant and Planner.

The development of the Plan, or Budget, also should be separated from the plan implementation. It is regularly reported that there is little or no support from the Local Area Coordinators to implement a plan. DSA therefore recommends that these two functions are separated to better support participants. Refer "Help Accessing Supports" below.

### Accessible information

NDIS information and access for people with Down syndrome and intellectual disability needs to be improved. This should include Easy Read and other alternative Easy to Understand information in relation to the access and planning processes, as well as use of plans. In particular, participants should be provided with, or at least be able to request, accessible plans (e.g., in easy – read or plain English using accessible graphs or diagrams to explain the plan). DSA would recommend looking more broadly than just Easy Read as a way to make information accessible. We endorse and recommend the use of the Listen, Include, Respect guidelines (<https://www.listenincluderespect.com/>).

### Specialist Planners

One of the most common criticisms of Participants or their families is that the NDIA or LAC staff “do not understand me or my disability”.

DSA recommends that the roles of NDIA staff and Partners (i.e., Planners, LACs and ECPs) need to be redefined in order to build confidence in the system, and that a key step in this process could be to expand the use of specialist planners.

Specialist planners could help address a number of different aspects that currently present challenges in the planning process. For example, planners could specialise in:

- The needs of First Nations Australians, people from culturally or linguistically diverse backgrounds, people who identify as LGBTIQ+, gender diverse people, where they can take that into account in planning (e.g. there may be an impact on things like informal supports due to cultural differences).
- Regional and Remote differences where participants may not have access to LACs, and ECPs, or to the same level of services.
- Specific disabilities or disability groups such as Down syndrome, or Intellectual Disability. For example, some people report in planning meetings that their Planner wasn't aware of the physical issues associated with Down syndrome and that it is more than just an intellectual disability. These planners would also be able to specialise in supported decision making, or augmented or alternative communication methods, to better support people with Down syndrome or intellectual disability to exercise choice and control over their plan.
- Specific transition points such as leaving school, getting a job, moving out of home where planners can understand and apply these specific (and often complex) NDIA supports to the individual circumstances of the participant.

### Supported Decision Making

Supported Decision Making needs to be incorporated into all aspects of the supports provided to a participant who requires this. This costs money and requires participants and decision supporters to be trained and experienced in supported decision making. This should be included in plans and as broader capacity building activities through, for example, ILC activities.

The NDIA Supported Decision Making Policy needs to be rolled out, along with training and support to all NDIA and Partner in the Community staff.

## A complete and joined up ecosystem of support

### Key principles / recommendations:

- Mainstream services have a role to play in supporting people with disability both on and off the NDIS.
- Mainstream services need to be held accountable and supported to deliver inclusive services under Australia's Disability Strategy.
- Advocacy and/or Disability organisations have the knowledge and can play an important role in connecting people with the most appropriate mainstream service (potentially under a program such as Ability Links).
- The Information, Linkages and Capacity Building program plays a vital role in providing services to people with disability outside of the NDIS and needs to be refreshed and be seen as a long-term commitment, not project based.
- The role of the NDIA and Mainstream services in the event of urgent changes in circumstances needs to be better defined and more responsive.

### The Role of Mainstream Services

Mainstream services should be available and accessible to all people with disability (on the NDIS and outside it) without discrimination, and people with a disability should be encouraged to access these services. This includes but is not limited to health, mental health, education, employment, housing, cultural and recreational services. These should be provided by the level of government responsible for those services; Federal, State and Territory and Local governments, as well as disability and community services and supports funded by the Government.

Individuals and families in need, at risk, or going through transition periods or change of circumstances often require more support in finding information about who is responsible for what. **Currently, it is patchy and difficult to understand, for example which system covers what (health/education etc) and who makes these decisions. This leads to frustration and outcomes that aren't the best for the participant.** Referral pathways need to be better defined and supported.

**From the perspective of a person with a disability, the ideal situation would be that they can access the supports they require (be that from within or outside of the NDIS) in their local area.** This could be facilitated by disability and/or community services providing those connections to the most appropriate services in their area, for their need (refer Help Accessing Supports below). **A model such as the previous Ability Links program should be reinstated.**

The levels of government, and related community services providing these services need to be connected to each other with responsibilities and accountabilities clearly defined so that they all know who should be providing what supports. **Australia's Disability Strategy can be used to hold these levels of government to account for delivering mainstream services that are inclusive and accessible.**

### Australia's Disability Strategy

Australia's Disability Strategy currently sits within Department of Social Services, it could benefit from being elevated to a higher level, such as Prime Minister and Cabinet to allow for more accountability by all parts of governments to implement.

DSA supports the concept of a Disability Office (as proposed by DANA and AFDO) within government to implement and oversee all of government's implementation of the Strategy and other disability policy and supports, including State and Local government services.

### **Information, Linkages and Capacity Building (ILC)**

ILC programs need to continue to be available to both people within and outside of the NDIS. These need to be delivered in partnerships between disability representative organisations and mainstream community organisations or services. DSA has provided the Review with a specific submission on ILC that includes benefits, challenges, and recommendations in this area.

### **Better definition of responsibilities and responsiveness to urgent circumstances**

DSA often hears of people who have urgent circumstance changes ending up in hospital as there is nowhere else for them to go. The NDIA and other Mainstream services need to improve the responsiveness to urgent circumstances, and better define responsibilities for the provision of changed supports when urgent circumstances arise.

## Defining reasonable and necessary

### Key principles / recommendations:

- Reasonable and necessary causes the most confusion in the NDIS.
- The concept could be removed if other aspects of plan implementation and measurement are improved.
- Different concepts could be applied to different aspects of funding.
- Consistency of application is essential to build trust and confidence in the system.
- Improved education and understanding are needed for participants and their families.

DSA concurs with the Review Panel's findings that this is one of the biggest areas of confusion and concern in the NDIS.

*"Some families seem to use the definition of what reasonable and necessary is too loosely, some are far too rigid. This seems like a lack of education and a far too complex system."*

Parent

### No reasonable and necessary

One approach could be to remove the requirement in its entirety. If an effective planning process is followed then by default, the dollars in the plan are all reasonable and necessary for the participant to spend on achieving their goals or receiving the supports that they require. The effective use of the plan could be supported by improved plan implementation supports (refer Help Accessing Supports below) and measured by looking at the outcomes achieved with the funding (refer Measuring Outcomes and Performance below).

### Different criteria for different components of funding

An alternative approach could be to have different principles and criteria for different areas of NDIS Plan funds. For example, core funding may need to meet necessary and reasonable criteria, while capacity building funding may need to meet a principle of enhancing social or economic inclusion, building identified skills and/or supported decision making, or achieving a goal. Similarly, some categories of funding could have no reasonable and necessary criteria as outlined above.

It would be important not to introduce unnecessary complexity through this approach by having too many categories and criteria.

### Reasonable and necessary or necessary and reasonable?

A more conservative approach could be to change the order which they are written: *Supports must be necessary and reasonable*. This puts the emphasis on the support being necessary before it is considered whether it is reasonable to be purchased with the funds which seems a more logical order.

**Defining necessary;** essential; needed to function in everyday life and be included (not necessarily goal related); needed to achieve specific goals.

**Defining reasonable;** evidence based; good value; fair; sensible and safe.

### Consistent application

One of the biggest challenges that participants and their families see with the application of reasonable and necessary is inconsistent application. Whether that be actual or perceived inconsistency, it reduces the trust and confidence in the system.

It is therefore important to be able to demonstrate that application of process is consistent across the board. This can be achieved by further guidance and training for planners/LACs, as well as things like specialist

planners as outlined in Applying and Getting a Plan above which would improve consistency by having some of the more complex aspects of the NDIA supports applied by “experts” in that field.

### **Improved education**

Whichever approach is taken, participants need more support around understanding their plan and how it can be spent. Some of this can be achieved through:

- Draft plan review as part of the planning process (refer Applying and Getting a plan above)
- Better support to implement a plan (refer Help Accessing Supports below)
- Improved education on the types of services that funding can be used for (refer Help Accessing Supports below)
- Improved education and support for Participants and delegates on what happens if funding is used incorrectly – i.e., to remove the fear component of being pursued for repayment in the event of an honest mistake or misapplication of the rules.

## Early childhood supports

### Key principles / recommendations:

- The Early Childhood approach needs to be true to the concept of “investing in people with a disability early to improve outcomes later in life”.
- The Early Childhood planning processes need to mirror the recommendations for the Planning process above including specialist planners and a separation of development of the plan budget and implementation of the plan.
- More consideration needs to be given to the family unit in Early Childhood; sometimes it is other family member who need to be able to access supports to best support the child with the disability, and the concept of parental responsibility needs to be more equitably approached.
- Services should be delivered in mainstream settings where possible.

DSA and our Members often hear that the current NDIS Early Childhood approach and system is often overwhelming and confusing for parents and families and does not provide the best supports for them in the early years of their child’s life.

There are a number of key areas of concern we hope the NDIS Review will consider. Many of these link to other priority areas raised by the NDIS Review.

### Investing early

The Review states that “The NDIS takes a lifetime approach to achieving these outcomes, investing in people with a disability early to improve outcomes later in life and improve system sustainability.” The early investment is critical, and easy to achieve in the case of Down syndrome as the condition is generally diagnosed before or very shortly after birth, giving the maximum opportunity to invest early.

DSA and its Members often hear of significant delays in newborn children with Down syndrome accessing the NDIS. Positive experiences generally relied on hospital staff and local Down Syndrome Associations linking parents with the NDIS. But sometimes hospital and others including NDIA staff were of no help.

*“So we first tried to get, our daughter onto the NDIS when she was about two or three weeks old, and I had a lot of difficulty because the social worker in hospital and everybody else that I’d spoken to, nobody could tell me who I had to contact or how I went about actually making those initial steps to get on.*

*Um, and then I had a lot of difficulty, I’d make phone calls and leave messages and they, they didn’t return message didn’t return my calls. So I’d be waiting weeks for them to get back to me to you know, guide on the next steps and what I had to do. At one point, somebody from the NDIA said to me, why are you trying to get onto the NDIS when she’s so little, she’s only three weeks old, you shouldn’t be doing this now you should wait till she’s older. You know, those sorts of comments, which I found really difficult to deal with at the time, because I just wanted, I knew that at the process took a long time and I wanted to get everything organised and ready to go, you know, I had newborn baby.”*

Parent

### Planning and coordination

Down syndrome is still not well understood by most NDIA early childhood approach (ECA) workers and planners. Newborn babies are often given an NDIS plan with only one or two developmental domains covered, despite the syndrome having evidenced functional impact across all 6 domains. There should be more investment in training for ECA partners (in line with the Specialist Planner approach outlined above).

Early Childhood Partners do not appear to be fulfilling the coordination role that the Scheme says they should (often due to extremely high caseloads). ECA partners are funded to connect and work well with peaks such as Down syndrome associations, however this rarely occurs due to these time constraints. The approach outlined below in Help Accessing Supports should also be applied in the Early Childhood area.

*“I’ve not received a single referral from an ECA partner in the 3 years I’ve been in this role, despite previous connections to them.”*

Down Syndrome State organisation staff member

### **More focus on supports for the family**

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.

### **More focus on supports in the community**

The planning process needs to consider the most appropriate supports for the child and the broader family and community. 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.

The Early Childhood approach needs to consider whether some of the early intervention supports required for a child are best delivered in a mainstream setting rather than in a therapist rooms. For example, many early intervention strategies can be delivered as part of a playgroup or play based session rather than one on one in a therapist room.

*“So, while we focus therapy on one person, we are kind of missing that opportunity to work with whole families, with linking with what’s happening at the school linking in with what happens in different community settings. So I think that if capacity building is going to have a focus on supporting an individual to grow and progress and build their capacity, we need to think outside of just that individual because how that person interacts with their family, the school and the community is really important.”*

Parent

### **Family support**

Place-based, wrap-around family support should be universally available across Australia to any family wishing to access it. Currently, many family support services are ‘targeted’ at vulnerable families and can carry an associated linkage or stigma in relation to those at risk of domestic and family violence and child safety risks.

We know that experiences such as perinatal mental health, for mothers as well as fathers, are universally experienced, regardless of sociodemographic factors; and this is particularly so if you’ve received a prenatal or postnatal diagnosis of disability for your child.

If an ‘it takes a village’ approach could be built into universally available new parenting supports (with a higher level of such support immediately available for those families whose child is born with, or diagnosed during early childhood, with a disability), this could go a long way to strengthening the wellbeing of children and their families across Australia.

This could be delivered in non-stigmatizing existing locations, such as schools, libraries, community centres and with a virtual platform for more isolated families, and funded outside NDIS plans (e.g., as Tier 2 supports).

### **Access to services, supports and equipment**

The lack of availability of therapists and allied health professionals is an issue for many families and children on the NDIS. It is an issue particularly evident in regional and remote areas. The government, via the NDIA, needs to consider how to increase the pool of professionals so that children can access the supports which they require, or increase the use of and access to Allied Health Assistants.

### **Parental responsibility**

The idea of 'parental responsibility' needs to be reconsidered and applied more equitably. It is not equitable to compare the responsibility of a parent of a child with Down syndrome or other disabilities to that of a parent of a child without a disability. Parents are often being told 'that is parental responsibility' when asking for additional support.

A parent to a child with a disability may have the same responsibility as that of a child without a disability however it does not have the same impact on their everyday life. Home life for a family of a child with a disability can be very different to home life of a family with children without disabilities. When parents are told that a support, which would support not only the child with the disability but the broader family, is their responsibility it leads to stress, a reduced willingness to reach out for assistance and worst-case carer burnout. Easier access to respite care (or similar supports) and earlier intervention for families at risk of burnout is needed.

## The support and service marketplace

### Key principles / recommendations:

- Many roles, in particular support worker, are seen as ‘transitional’ or short-term roles and are there is little incentive to remain in the role or provide a quality service.
- Pricing does not incentivise delivering outcomes for participants, it just supports delivering a service.
- There needs to be increased flexibility on the use of funds in thin markets.
- A new pricing structure is needed to ensure that participants with complex needs can access supports.
- A strong NDIA and Partner in the Community team is vital to the success of the NDIA.

The NDIS Support and service marketplace is complex. Factors that contribute to this complexity include:

- Size of providers – from sole traders to large national providers
- Location of providers – from urban to rural and remote
- Competition levels – in some areas there may only be one (or no) provider, others there may be multiple providers.
- Registration status – registered and non-registered providers
- Range of services - some providers just provide one service, others take a “one-stop” shop approach to service provision.

The above factors contribute to many of the challenges we see in the NDIS marketplace from poor quality providers, providers appearing to just focus on getting the most out of a participant’s plan, and workers who are not skilled or trained in their roles.

### Increase the appeal of working in the disability sector

Many roles, but support work in particular, is often to be perceived as an “in between” job i.e., a good option when you are studying or as a part time role, but not a long-term career.

Increased awareness and promotion of the benefits of roles in the disability and human services fields, including options of career advancement would raise the profile of these roles and increase how they are seen as a valued profession. This would further ensure those with an interest and passion are employed within the sector, building trust and confidence with participants.

### Change the pricing model to support outcomes

A common issue expressed by families is that support workers aren’t supporting their loved one. They are acting like glorified babysitters and are not incentivised to build the capacity of their loved one as this essentially means they will be out of a job. They are not trained to know what genuine support looks like - the “With Us, Not For Us” approach. As outlined in Measuring Outcome and Performance below, a pricing mechanism that rewards outcomes would assist in supporting genuine support work being delivered.

### More flexible funding in thin markets

In thin markets, where suitable supports are not always or not consistently available, the flexibility around how funding is used should be increased, including the ability to move funding across domains or across support categories. For example, in some situations being able to employ family or household members to provide support if a suitable support worker is not available could be an option.

Further reviews of pricing structures for rural and remote services should be undertaken to attract suitable supports, or alternatively consider paying a levy for service providers in areas where there is a particular shortage to encourage supply.

### **New pricing structure for complex needs including therapists and support workers**

The NDIS marketplace in many areas is very competitive, particularly for supports such as therapists and support workers. This can often lead participants with complex needs unable to get suitable supports as they can be seen as “hard” clients and the provider can get paid the same rate to work with a less complex participant.

Additional tiers of pricing that sit between the standard pricing and High Intensity Supports pricing need to be developed to address the above issue.

### **Partners in the Community and NDIA staff**

The marketplace for, and staff retention in, the NDIA’s partners in the community and also the broader NDIA also has an impact on the support marketplace. The capacity of the NDIA and PIC workforce also needs to be considered as part of the Review.

DSA was pleased to see additional funding on workforce capability included in the May 2023 budget, and we encourage the review to emphasise in their Report the importance of a properly trained and supported workforce that has the time, capacity and the culture to not only support participants but to support the inevitable changes that will come from the NDIS Review.

*“The planners really need to have a genuine desire to help and not be the gatekeeper. I find it really difficult when you’re met with no reasonable discussion around what can be explored. And also, they need to bring in energy. Sometimes we’re at the end of our tether and they need to be the ones that are offering ideas and support rather than, again, just being the gatekeeper.”*

Parent

## Measuring outcomes and performance

### Key principles / recommendations:

- Participants need a better way to be able to know a good or poor provider and to be able to assess if they have delivered on the outcomes the participant is seeking to achieve.
- Pricing models should motivate outcomes not just delivery of service.
- More focus and measurement need to be put on capacity building supports which provide outcomes.
- The use of goals needs to be refined.
- The NDIA needs a better framework for measuring outcomes for a participant and the broader community – this will help shift the focus from purely what the NDIS costs.

### Performance of Providers

Participants need to have a way of knowing a good provider from a poor provider and whether they can provide services that will meet their needs or deliver a good outcome. **A rating or review system should be implemented to enable that feedback to be recorded and shared with other participants.** Individuals could self-assess or self-rate services and their ability to meet their needs. Participants also need to be able to easily leave one and go to another provider, if that is the path they wish to pursue, without any barriers being placed in their way by the providers.

Providers all too often are motivated to provide any service they can to the participant, even if that is not what is required, or is not a service which meets the participants needs. The proposed approach of providing additional help to access services (refer Help Accessing Supports below) would assist in this space in supporting participants to exercise their choice and control. Furthermore, consideration should be given to providers having to give more information on how supports have aided the participant.

### Pricing models to incentivise outcomes

Providers aren't incentivised to work toward completing a goal as this means that the participant could no longer require their support. Pricing models should be reviewed to provide mechanisms for paying for outcomes rather than just for delivering a service.

**This approach lends itself best to capacity building supports.** For example, a **staged payment process** could be made based on steps towards a larger goal, or a "bonus" paid when a goal or outcome is achieved. An example could be support workers incentivised to deliver travel training that leads to a participant being able to navigate public transport independently.

### Use capacity building funds to drive outcomes

All too often funds to support, for example, daily living tasks are provided as Core where there should more often be a capacity building component to these supports (where appropriate) to motivate an outcome of increasing the capacity of the participant to perform that task, or aspects of that task independently.

As part of measuring outcomes, the **NDIA should look to motivate this by providing more capacity building funds where that is appropriate in place of core funds to reflect that there is a goal to build capacity rather than to just support the execution of a task.**

### Refine the use of goals

Currently a lot of the planning process and use of plans relies on participants setting goals – yet there is very **little, if any measurement of outcomes against those goals.**

DSA would recommend that goals may not be necessary for Core supports but should be retained for Capacity Building supports with an effective measurement process included so that progress against goals can be measured and reported on.

### **Measuring outcomes**

The NDIA needs a framework that simply and equitably **measures the outcomes of receiving NDIS supports for the individual, but also for the broader community and the economy.** A measurement framework just looking at the outcomes for the individual has the risk of continuing the focus purely on the cost of the NDIS, not the benefits that the NDIS brings. Therefore, an outcomes measurement framework needs to be able to demonstrate what benefit (outcome) has been given to the participant and at what cost, and also the consequential benefits such as enabling the participant, or a family member to work, or reduce reliance on certain supports, or change the supports that are required due to the funding that has been provided.

It is important that any such outcomes measurement framework is also socialised with the general community so that they can understand better how the NDIS supports people with disability and so that they do not just consider the NDIS as a drain on their tax dollars. It would be good to see some of these measures incorporated into the Wellness Budget that is being rolled out.

## Achieving long term outcomes

### Key principles / recommendations:

- Goals are a good way of achieving long term outcomes if they are appropriately supported by funding and measured.
- Planning and funded supports need to prioritise inclusive and community-based options above segregated settings
- Participants need to receive appropriate supports that their family members can take their appropriate roles in their connections with the participant and not have a conflict with their carer and family member role.
- Participants need to be supported to try different employment opportunities.

### The use of goals

As outlined in Measuring Outcomes and Performance above, the use of Goals as part of the planning process needs to be improved.

DSA would recommend some form of goal setting remains in the context of capacity building supports but is better defined and measured against so that progress can be identified, celebrated and supported. Goals should be short, medium and long-term to ensure that a scaffolding approach is taken to achieving long term goals.

### Community connections

Services and supports such as day programs (that operate under a range of names) and Australian Disability Enterprises that group people with intellectual disability are inconsistent with supports provided to people with other disabilities.

These supports do not nurture connections to local community and are not necessarily the best way to help people make friends, stay connected or learn new skills.

DSA recommends that these segregated services and supports are not put forward as a default for people with intellectual disability, and that participants are made aware of other more inclusive or community-based options available to them. DSA acknowledges that this is a long-term goal and that many people are either comfortable with these services, or there are few genuine alternatives available.

*"There will need to be a transition plan or alternative services that people can access. Given the lack of available support workers, group/day programs are a lifeline for families who have adult members with disability that need support/supervision during the day."*

Down Syndrome State organisation staff member

### Connecting with family

The NDIA continues to quote "parental responsibility" or "expected level of care" as a reason for not funding supports well past a participant becoming an adult.

To develop and maintain genuine connections with family members (parents, siblings etc), there must be the appropriate supports funded in plans to reduce this conflict between the role of carer and family member.

To not properly fund the appropriate supports is also more likely to lead to carer burnout and cost the scheme more in the long run.

### Employment

Employment is one of the biggest challenges people with Down syndrome face. Funding to assist with work experience, and/or part time or casual jobs at school would assist not only in building the capacity of the person with Down syndrome and helping them identify what employment opportunities interest them, it will

also assist in breaking down the negative community attitudes towards employing someone with Down syndrome.

Other changes also need to occur at systemic level in related mainstream services such the Disability Employment Services and Centrelink to further support employment of people with Down syndrome. Down syndrome Australia's ILC Employment project has identified the important role of a specialised employment connector with experience and expertise in intellectual disability as a key enabler to employment outcomes.

## Help accessing supports

### Key principles / recommendations:

- Supports to implement a plan should be separated from the setting of the plan budget.
- Participants need better supports to make best use of their plan in order to achieve their goals.
- These supports should be provided outside of the funded plans and can be provided by disability or community organisations many of whom are already fulfilling this role.
- Supported decision making needs to be incorporated into all aspects of plan implementation and should be funded in participants plans.

### Separating Plan Development from Plan Implementation

As outlined in Applying and Getting a Plan above, DSA is recommending that the role of developing the plan (the Plan Budget) is separated from support with plan implementation (or navigating the NDIS).

The current NDIS approach is to give a plan and then say "see you next year" (or in 2-3 years). Participants might get a Support Co-ordinator to assist in the implementation and management of their plan but regardless, when a plan is given, everyone should have the opportunity to receive support to implement that plan in the best way for them.

This could include assistance with how to use the plan, as well as support around whether supports are working and what other things they could try. The role would also lend itself well to providing participants with the support around reasonable and necessary as outlined above, as well as the overall navigation of the NDIS and broader mainstream supports (refer A complete and joined up ecosystem of support above). This support may not be needed to the same degree by all participants depending on their confidence, time on the scheme, stability of supports, upcoming transition periods etc but should be available if required.

The role could be delivered by 3rd parties (who get bulk/block funding) from the NDIA. The role does not have to be provided by Partners in the Community; in fact it should be considered whether they are the most appropriate people to provide these supports. Many disability organisations are already fulfilling much of this role, in many cases unfunded, due to the lack of these connection and support services being provided by the Partners in the Community. DSA would propose that there are local organisations who can provide the generalist support in the implementation of a plan, for example the types of services that can provide supports and connecting to those services in the local community. These generalist supports should be supplemented by specialist supports for specific cohorts or life stages such as transition from Early Childhood to full scheme, from School to Employment, Independent living etc.

One of the benefits of using disability organisations who are already proficient in many of these areas is that they also provide the opportunity to connect participants to peer support from people in a similar situation around how others are using their plans. DSA has found that many people like to hear, and benefit from understanding and sharing how others are using their plans and what supports they are accessing. This also builds the capacity of the participants and their support networks.

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.

*"Knowing how to trust someone is very difficult. It takes time, I have trust issues"*  
Participant

## Supported living and housing

### Key principles / recommendations:

- Implementation of the Home and Living Policy should be prioritised as part of the Review outcomes.
- Participants who need a lower level of support to live independently should not be forgotten.
- Current Home and Living options available need to be supported by specialists who can support participants to navigate them.
- Group homes should not be forced on participants as their only option.
- Innovative solutions can be encouraged by using peer mentors, in conjunction with the NDIA to support and promote innovative ways that other participants have navigated home and living supports.

DSA acknowledge that housing is not just an NDIS issue. For many people with disabilities, as with the general population, there is simply no housing for them to go to. Finances play a significant role in this for people with Down syndrome as many do not earn enough for a bank to approve a mortgage, and they face additional barriers when it comes to renting in addition to affordability, including prejudice against renting to someone with a disability.

There is also a massive undercurrent of fear in families given how quickly the cost of living is increasing, instability of housing, cost of renting and the lack of appropriate support workers and the lack of Government funded individual disability housing.

### Implementation of Home and Living Policy

DSA is part of the Core Design Group for the Home and Living Policy and whilst we understand that this has been put on hold pending the Review, we encourage that this Policy is implemented as part of the review outcomes.

We also note that it is critical that participants who need a lower level of supports for Home and living are not forgotten about and that their needs can be properly accommodated through the existing planning process.

### Confusing support options

There is significant confusion amongst participants regarding the NDIS supports for living and housing. Most people with Down syndrome will not qualify for Specialist Disability Accommodation, but Supported Independent Living and Individual Living Options also require a high level of support (minimum 6 hours per day) for it to be funded which in itself would disqualify a large portion of people with Down syndrome who want to move out of home, or conversely cause them to overstate the support requirements in order to access these categories of housing support.

Many people with Down syndrome can therefore “slip through the gaps” in terms of a housing solution, as they still require supports to move out of home but may not be eligible for SIL, ILO or SDA.

There is not enough understanding of Housing support options and in particular ILO from planners so people are not exploring ILO options nor are they getting ILO funding in their plans and sometimes ILO doesn't meet a persons needs and also can be limiting. Some people are better off just having good funding in core for them to be able to use it flexibly and proactively to explore their independent living options.

### **More specialist planners**

There is a need for interim funding for SIL and SDA while a person is transitioning or just starting out to find out what their level of support is needed to take the guess work out of it. Promotion and championing of Specialised Housing Coordinators to assist families and people with disabilities to explore and feel supported in making such big life decisions would be beneficial.

### **Solutions need to avoid segregation**

More focus needs to be put in inclusive living settings. Supported living and housing can tend to default to putting participants with similar support needs together as a way of reducing costs and sharing supports. Choice and Control needs to be applied and respected to ensure that participants are not being forced into these living situations due to funding or other constraints.

### **Use peers to support innovative options**

Many participants or their family members have, through need, identified innovative ways of implementing home and living supports. Our members report that it is often useful for them to hear about things that others have done to support independent living. **Peer mentoring or coaching should be implemented, supported by the NDIA using participants and their family members who have been successful in implementing innovative home and living supports.**

## Participant safeguards

### Key principles / recommendations:

- The current approach of provider registration provides little incentive for providers to become registered which increases the risk for participants. This needs to change.
- People with intellectual disability need to be supported better to understand their rights.
- **Reporting needs to be easier and more accessible.**

### Registered vs unregistered providers

There is very little motivation to become a registered provider in the NDIS, and as unregistered providers are not required to meet the same criteria around quality of service, the safeguarding of participants is put at risk. Furthermore, participants generally do not recognise the benefits of using a registered provider (i.e., they are not aware of the safeguarding risk).

There needs to be better education to participants on the difference between registered and unregistered providers so that they are making an informed decision on whether to use an unregistered provider. This could be incorporated into the approach proposed above in Help Accessing Supports.

**Different tiers of registration should be introduced that make it easier for some unregistered providers to become registered such as a sole trader doing support work only for example could have a lower registration requirement than a large organisation providing complex supports such as Specialist Disability Accommodation.**

Pricing models should recognise the increased impost of being a registered provider and benefit providers for registering – this cannot be done through pricing that comes out of a Participants plan as that will lead to the wrong outcomes. The Review should consider providing incentives to providers to become registered e.g., by covering their audit costs.

### Better supports for people with Intellectual Disability to understand their rights

People with intellectual disability need to be supported to understand their rights, how to report incidents or concerns and make complaints, and importantly feel safe doing so. 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). Support for decision making is key to safety and dignity of risk, as described above in the outcomes area.**