



# What we have heard

Making a submission on solutions

June 2023



# Submission questions

This document provides the questions associated with the What we Have Heard report. You can use this as a template to draft your answers or upload this document to [the Have your say survey portal](#).

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

This report is designed to open up conversations on the topics you have told us affect you most and the ones we have identified as part of our early explorations. We welcome your feedback on what we have prepared, as well as topics you feel need further examination.

Between now and 18 August, we look forward to engaging further with you as, together, we find solutions we can present to governments.

I am the mother of an extraordinary 25-year-old woman, Lilian, who is brave, optimistic, energetic, social and loves unconditionally. She lives with a complex brain injury sustained at eight weeks old through bacterial meningitis and has fought for her life many times. It has impacted her physically, intellectually, and mentally. She has eight diagnostic labels, none of which define who she is, what she can achieve or what her needs are. Lilian lives with two housemates, and SIL funding enables this. We have accessed the NDIS for 8 years, we are so grateful to live in Australia and feel an enormous sense of urgency to stop the abuse and misuse of NDIS funding and improve the system for those who access it. My daughter is thriving because of the opportunities and independence the NDIS has afforded her. She is living her best life.

# 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, and that there is little trust or confidence in the way decisions are made.

## 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?

For the NDIA to make decisions about eligibility and what supports will be funded, they need to clearly understand what the disability label/diagnosis means for the person and the people who live with it. A generic diagnostic label means little in this context, e.g., cerebral palsy, yet every person with cerebral palsy is impacted differently. It depends on a whole lot of aspects, such as medical, physical, intellectual, environmental and relationships. What is working and what is not, and what are the barriers to living a good life? This starts with a conversation, preferably face to face with a LAC. This LAC needs to be your regular contact and the conduit between us and the NDIA. It stops repetition, loss of documents and unnecessary administration. This ongoing relationship would stop most of the stress, frustration and distress often experienced throughout the planning process due to inefficiency and impersonal processes.

## 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 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?

An ecosystem of support is accessed through community hubs. Prior to NDIS, NSW local area health centres and ADAHC provided a fundamental support service to parents/carers. It had access to therapists, social workers and educators to advise and support parents. It was there, at the John Williams centre in Wahroonga, that I was given hope. I was guided on how to help my daughter recover and thrive by the same people for 45 mins each fortnight. I attended group information sessions on services, and was educated about best practice. I borrowed resources and equipment instead of purchasing it, and returned it when no longer needed for another family to use . I met other mums who understood my grief, anxiety and the life we now lived, and we cried on each others shoulders. The social worker assisted me to access local services, community activities and most importantly respite, which saved our family . These women, 25 years later are still my friends and core to my support circle. I am hopeful that the Governments Carer Gateway service <https://www.carergateway.gov.au> is a good platform to start these links.

### 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 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?

This is difficult because we all think differently and have different expectations of what NDIS should fund. I think the best way is to give real life examples of what is reasonable and necessary e.g A wheelchair is reasonable and necessary, but an additional beach wheelchair possibly isn't because they can be hired. Funding families to go on overseas holidays is not necessary...

Expensive annual reports from allied health professionals are NOT necessary annually if a person's needs have not changed. I keep saying there are not cures for my daughter's disability.

## 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 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?

The key to success for any child with a disability or delay is **learning**.

The discovery of **special education** when my daughter was 3 years old was life-changing for her and us as a family. It changed our path for her and future thinking.

Children don't need to be bombarded by expensive weekly therapy to "fix them" – they need to be taught in a way that makes sense to them and meets their individual learning needs.

They need to be with their "typical peers" in natural settings and included in all daily routines of the childcare/preschool.

The educators and family members need to be coached and mentored by a **special educator** to develop **an ILP (Individual Learning Plan)** to ensure that they have the strategies and capacity to include and teach these children.

This means that young children with, or at risk of, developmental delay or disability are likely to have better outcomes when the adults with the most influence in their lives (their families/carers and early childhood educators) are, through capacity building, empowered to support the child's participation and engagement in learning

opportunities within their natural environments (such as home, local community settings like parks and shops, and early childhood education and care services.

[REDACTED]

## 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 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?

The behaviour of providers is disgusting. The business mentality to make a profit (price gauge) as opposed to providing evidence-based service as needed has become a pandemic. Unnecessary reports that are based on a "template" need to stop. The people who engage these service providers need to be supported to make informed choices about what they want and need not be bullied into providing their entire funding to one provider. For those unable to access service...online or phone support is another option and helpful when done well and a relationship is established with the provider.

The workers need to be remunerated properly. They are the people on the ground delivering the care/learning. Compare a therapist charging \$200 p/h to simply deliver instruction to the support worker/educator who is paid 25% of that. The inequity is wrong. I just don't understand why the common belief is that everyone needs speech and/or OT.

Stop asking people to repeatedly prove their disability annually...the only people who benefit is the providers.





## 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 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?

**Insert your response to this question**

## 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 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 change to make this work better?

I think the goal setting and annual review report is good. It just needs to stop being tokenistic and really reflect the needs and aspirations of the person with the disability. I ensure my daughters NDIS goals are relevant to her and these plus her restrictive practices and learning goals are incorporated into her ILP which is implemented across her day program, home and community settings. Similar to what the NDIS refers to as being a support plan.

## 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 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?

**Insert your response to this question**

## 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 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?

**Insert your response to this question**

## 10. Participant safeguards

We are concerned to learn that the NDIS may not have worked well enough to safeguard all participants, while making sure they can still have choice and control. More can be done to empower participants to keep themselves safe, and ensure systems are working together to improve safety and outcomes.

### 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?

**Insert your response to this question**

## 11. Any other information you would like to tell us?

Insert your response to this question