

WHAT WE HAVE HEARD SUMMARY REPORT

From defining problems
to designing solutions
to build a better NDIS



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Introduction from the co-chairs

As you know, Disability Ministers have asked us to review the NDIS.

We especially want to improve the experience of participants and ensure the NDIS is sustainable.

In this report we:

- outline what we have heard from you so far
- draw out five key challenges we have been thinking about
- highlight 10 areas you have identified for improvement.

For each area for improvement we want to know your ideas to change the NDIS. We are looking for your solutions.

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

Have your say at

www.ndisreview.gov.au.



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.

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 learnt so far

"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

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.

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.

This includes 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 best to make reasonable and necessary clear and put it into practice. We want to know how to make sure 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. There appear to be a few reasons for this. One is that the original estimates were too low. It also reflects a lack of support for children with disability in mainstream settings outside the NDIS.

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 along with the lack of support for children outside the NDIS means children are not always getting good outcomes. It is also putting pressure on the sustainability of the scheme.

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.

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. 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 announced 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.

You can send us your ideas a number of different ways. You can answer our survey. You can attend an in person or online session 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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Co-chair

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Co-chair

Independent Review of the National Disability Insurance Scheme



Priority areas for improvement

We have identified 10 areas where the scheme needs to change.

These areas do not work in isolation. They are connected and are part of the overall picture.

Some of these issues speak to poor experiences and outcomes for participants. Others contribute to the scheme's cost.

We will focus our efforts on addressing problems that benefit all participants.

At the same time, we won't lose sight of the big picture and improving the system as a whole.

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. There is little trust or confidence in decisions.

How can we empower you through

the planning process?

A complete and joined up ecosystem of support

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. People fall through the cracks and miss out on much needed support.

What is the best way to provide supports

for those not in the NDIS?

Defining reasonable and necessary

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

How would you define reasonable

and necessary, and put it into practice?



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 is the best way to support children

with disability and those with emerging

developmental concerns?

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.

How can the markets be better designed,

structured and supported?



Measuring outcomes and performance

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

How should outcomes and performance

be measured and shared?

Achieving long term outcomes

We have observed that there is a lack of focus on achieving long term outcomes relating to participation, inclusion and employment.

How would you like to build better outcomes

into your plans?

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 does good service from someone

helping you navigate the NDIS look like?

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.

How should housing and living options

be improved to build a good life?

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 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.

How should the safeguarding system

be improved for a better NDIS?