

Avoiding simple solutions to complex problems: Independent Assessments are not the way to a fairer NDIS

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For Children and Young People with Disability Australia

May 2021



UNSW
CANBERRA



Public Service
Research
Group



Melbourne Graduate
School of Education



**Children and Young People
with Disability Australia**

Suggested citation

Dickinson, H., Yates, S., Smith, C., Doyle, A. (2021)
Avoiding simple solutions to complex problems:
Independent Assessments are not the way to a
fairer NDIS. Report prepared for Children and Young
People with Disability Australia (CYDA), Melbourne.

ISBN: 978-0-6489169-2-5

Acknowledgements

Children and Young People with Disability Australia and Professor Helen Dickinson, Dr Catherine Smith and Dr Sophie Yates and Ms Alana Doyle would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was, and always will be Aboriginal land.



Australian Government

Department of Social Services

This activity received grant funding from the
Australian Government.

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Executive Summary

Experiences with the National Disability Insurance Scheme (NDIS) can vary widely. Positive experiences with the Scheme can be life-changing or transformational for children, young people and their families, supporting their human rights and facilitating their goals. But at the moment, the NDIS doesn't work for everyone. There are a range of inequities within the Scheme that lead to divergent outcomes and experiences for NDIS participants.

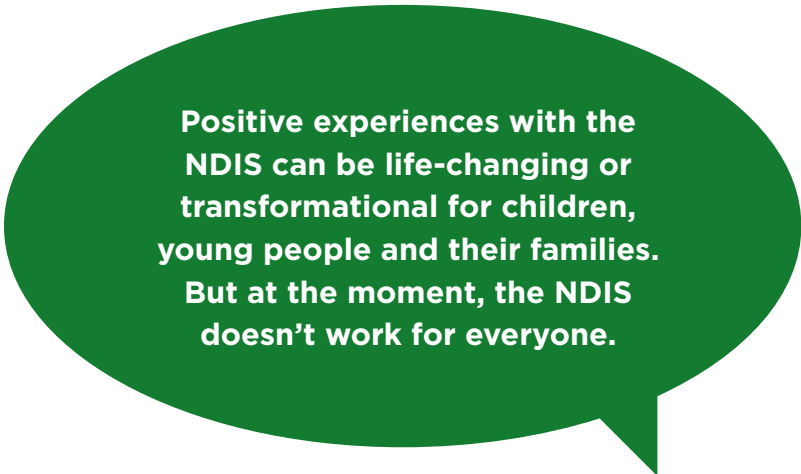
The Federal Government has proposed the most significant reforms of the NDIS since its launch. One key part of this reform process is the introduction of Independent Assessments. The Independent Assessment process involves functional assessments being administered by a professional who is unknown to the child or young person. The result of an Independent Assessment then determines the funding that is allocated to the child or young person for their supports.

The government states that this approach will make funding decisions clearer and more consistent. Many critics agree that the NDIS can be inequitable and that this needs to be addressed, but also have concerns about the use of Independent Assessments as a way to address these problems. There is widespread concern that the planned Independent Assessment roll-out is underpinned by financial concerns and "scheme sustainability", rather than making the NDIS fairer for everyone.

CYDA surveyed children and young people with disabilities and their families to understand their experiences accessing the NDIS and their thoughts on the proposed reforms. This report sets out findings from the 270 people who completed the survey between 21 January and 21 February.

The survey was designed by CYDA and invited children and young people and families to share their experience of the NDIS, what works well and what should be changed. Participants were also asked about whether they had heard about Independent Assessments and what they thought about them.

For some young people and families, the NDIS is invaluable and has a significant impact on their lives; the scheme allows people to live the lives that they want. The financial relief the NDIS offers and greater access to services and supports has allowed individuals to develop their skills and engage with their communities in meaningful ways.



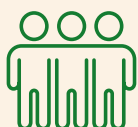
Positive experiences with the NDIS can be life-changing or transformational for children, young people and their families. But at the moment, the NDIS doesn't work for everyone.



SURVEY RESPONDENTS

88%

of respondents were **families**



94%

of **family respondents** were **female**

12%

of responses came from **children and young people**



Two thirds of the **children and young people** represented in the survey were **male**



NDIS PLANS

88%

of respondents were **currently receiving supports** through the NDIS



60%

of our sample **self-managed their plans**

15%

were on their first plan

over 50% were on second or third plans

16%

had five or more plans

The fact that the Australian community has chosen to invest in the NDIS has in itself made some children and young people with disability and their families feel less alone and more visible, heard and valued.

While the NDIS works well for many children and young people and their families, unfortunately this is not the case for everyone. For some the NDIS is highly stressful and uncertain. Respondents reported feeling like they are in constant battles with the scheme and that there is a lack of consistency and continuity.

Nearly 40 per cent of respondents had experienced challenges with the application process. This was often a long and uncertain process and could be financially burdensome in demonstrating eligibility, even where individuals had been disabled since birth. Many found the system confusing.

Having secured access to the scheme, three quarters of our respondents had experienced challenges with planning processes. Planners were reported as highly variable, with some of very poor quality, as were Local Area Coordinators.

44 per cent of respondents were satisfied with the funding in their plan, although a further 40 per cent were not. Particular gaps were identified in the areas of personal support, therapy and capacity building supports, participating in the community, and assistive technology.

Over half of respondents had asked for a plan review due to insufficient supports and a further five per cent had escalated a review to the Administrative Appeals Tribunal.

Just under half (45 per cent) of respondents were satisfied with services and support, with just under 40 per cent indicating they were not satisfied. Many respondents had experienced challenges relating to thin markets, meaning they could not find suitable services and supports, including those that were appropriate for children and young people or worked to empower children and young people.

Nearly three quarters of respondents had heard of Independent Assessments, although only 10 per cent had first received this information from the NDIA. This seems to suggest that, for our respondents at least, the NDIA has not been as successful in communicating these changes as other sources, which is clearly problematic for a reform of this magnitude.

Of those who had heard about the intended roll-out of Independent Assessments, 80 per cent had a negative view, with just 6 per cent seeing this as a positive reform. Of those with a negative view, many were worried that an assessment of this type done by a stranger would not give an accurate picture of abilities for a range of reasons such as lack of trust, complex needs, and masking behaviours. Independent Assessments were seen by some as a duplication of effort and something that would put more stress on families.

Overall, we find little support for the introduction of Independent Assessments and the clear message that respondents think they will not address the issues of fairness and consistency that they are intended to achieve. Further, they will do little to address the many inequities we find within the scheme and may in fact make the NDIS less fair.

The results of our survey indicate the reform proposals are the wrong solution to the many complex implementation issues of the NDIS. We note the recent announcement from Minister Reynolds that the introduction of Independent Assessments has been paused and we cautiously welcome this, but still hold concerns about the process and any potential future roll-out. The current pilot of Independent Assessments does not have a robust independent evaluation where the results of the assessments are compared to other evidence of functional need, nor are they testing the impacts on NDIS plans and budgets. We hope that the Federal Government hears these messages from children and young people with disability and their families and commits to abandoning this reform, engaging in meaningful co-design to overcome the issues currently experienced with the scheme, and ensuring that all people with disability receiving support have the same positive experiences that some currently enjoy.

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Introduction

As the Federal Government has argued, there are inequities in the operation of the NDIS that means not everyone is able to gain the advantages of the Scheme in the same way. In order to deal with some of these inequities the Federal Government has signalled intent to embark on the most significant reform of the scheme that we have seen since its launch. A key part of this reform process is the introduction of Independent Assessments.

In this document we set out data reporting experiences of the NDIS from 270 children and young people with disability and their families and caregivers. These data were collected by Children and Young People with Disability Australia (CYDA), the national representative organisation for children and young people (aged 0–25) with disability. CYDA is a not-for-profit community organisation that provides a link from the direct experiences of children and young people with disability and their families to federal government and other key stakeholders. CYDA sought to understand the experiences of individuals accessing the scheme to better understand the positive impacts this has on people's lives and some of the challenges that have been experienced. The survey also asked whether individuals had heard of Independent Assessments and their views on this proposed reform.

As might be expected with a scheme of this size, our findings indicate mixed reports on the NDIS. For some it has been life changing, yet for others there have been a series of barriers and challenges that have left children and young people and their families stressed and frustrated. These issues range from eligibility for and access to the scheme, to the planning process, Local Area Coordinators, size and content of plans, review processes, and actually being able to spend allocated budgets.



As might be expected with a scheme of this size, our findings indicate mixed reports on the NDIS. For some it has been life changing, yet for others there have been a series of barriers and challenges that have left children and young people and their families stressed and frustrated. These issues range from eligibility for and access to the scheme, to the planning process, Local Area Coordinators, size and content of plans, review processes, and actually being able to spend allocated budgets.

The proposed Independent Assessments will do nothing to address most of these issues. Overall we find respondents very negative towards these proposed changes, fearful of what this process might expose them to and concerned about the potential for them to have much needed care budgets slashed.

This report is structured as follows. The first section sets out the background, describing Independent Assessments, what these are and why the government believes them to be necessary. We then provide a brief overview of the approach used to generate and analyse the data in the report. We next give a picture of the demographics of those who responded to the survey, before moving to the findings. Here we set out the positive impact that the NDIS has had for some, and then detail the challenges reported by respondents in relation to various aspects of the scheme. Finally, we set out the implications of these findings in relation to the impact that the Independent Assessments reform might have.

Background

The NDIS is a world leading reform, which has been delivered at great speed. It is a huge achievement that there are more than 400,000 individuals being supported by the Scheme in just seven years and that children and young people comprise 57 per cent of all NDIS participants (National Disability Insurance Agency 2020b).

Large schemes like this are not static and go through changes to iron out problems and ensure that they are sustainable (Dickinson 2017). In 2020 the government announced the “most substantial package of reforms to the NDIS since its establishment” (National Disability Insurance Agency 2020c) and one of the many suggested reforms was the introduction of discretionary Independent Assessments. In this section we briefly outline what these are and why the government argues they are necessary to improve the NDIS.

It is estimated that only about 10 per cent of the 5 million Australians with disability will be eligible for NDIS funding and in order to meet the eligibility criteria, applicants need to demonstrate a permanent and significant disability. At the moment applicants do this by submitting evidence from experts such as medical professionals and specialists. But this can be costly to do and the government argues that this has led to inconsistent outcomes in funding. For example, former NDIS Minister Stuart Robert recently shared Tasmanian data showing a 53 per cent difference in the average value of NDIS plans between more and less wealthy towns. He argues that the amount of money that NDIS participants receive shouldn't be determined by where you live and Independent Assessments will make it “simpler, fairer and more consistent for participants, and their families and carers” (Robert 2021). It is true that the cost of gathering evidence to access the scheme can be expensive, however this reform proposal will not remove the need for this entirely. Under the proposed process, individuals and families still have to demonstrate they are eligible for the scheme before they move to the Independent Assessment stage.

The introduction of Independent Assessments will change the way that individuals are assessed once eligibility for the scheme has been established. Rather than relying on access lists and planners as the current scheme does, independent functional assessments will instead be undertaken. These will be done by one of eight organisations privately contracted to the NDIA, who will send an allied health professional to assess the level of support they need. The assessor will not be someone the person with disability already knows. The assessment will be done using a series of standardised tools and according to the NDIA will take around three hours. The tools assess what individuals are and are not able to do in terms of specific standardised tasks, with no discussion of individual goals. The outcome of this process determines if the person is eligible for NDIS funding and how much they should receive. The assessed individual will only receive a copy of the independent assessment report if they specifically request one. If allocated a budget at this point, the individual will meet with a planner. Under current proposals, the result of the Independent Assessment cannot be appealed.

However, the reforms for Independent Assessments go beyond proving eligibility for access to the scheme. The Government and the NDIA have proposed making these assessments compulsory for all current participants, who have already proven lifelong disability. To date, some current NDIS participants have been asked to volunteer to undergo Independent Assessments as part of the piloting process, although very limited detail of these pilots has been publicly released. In the first stage (originally planned for mid-2021 but now paused for potentially six months or longer) all people over 7 years of age that meet the initial access requirements will be referred for an Independent Assessment. Children under 7 with disability are covered under a specific Early Childhood Early Intervention (ECEI). Those currently in the scheme will progressively be required to undergo the same assessment before they receive their next plan. There has also been the suggestion that Independent Assessments might be extended to children as young as 12 months in the future.



According to the NDIA, functional assessments were always central to the implementation of the NDIS (National Disability Insurance Agency 2020d). Independent Assessments were originally recommended by the Productivity Commission in their blueprint for the scheme (Australian Government Productivity Commission 2011). Independent functional assessments were first trialled by the NDIA in 2012, but the trial found the tool not fit for purpose. A number of trials of tools have been undertaken since this time (see Bonyhady 2021), but greater discussion around this was sparked by an independent review of the NDIS Act known as the Tune Review (Tune 2019). This identified a number of problems with the NDIS at the time, and provided data from a pilot project that suggested independent functional assessments could help solve some issues. However, the process surrounding the assessments proposed in the Tune Review differ from those being suggested in the current reforms in some important ways. Specifically, there is: a lack of co-design and proper consultation; a lack of discretion in Independent Assessments to ensure they are consistent with the NDIS Act; and, a lack of protections such as a participant's right to challenge

assessment results. The proposed reform is not just about access as it will also be rolled out to those participants who have already proven lifelong disability as part of plan renewal processes.

There has been widespread condemnation of both the proposed Independent Assessments and the process through which they have been introduced in the disability community (see Dickinson 2021). Critics of these proposals argue that the tools are not appropriate for this process as they were not designed to aid decisions about funding allocations. Indeed, there is no other system in the world that uses functional analysis tools to allocate funding to people with disability. Many in the disability community are concerned that the introduction of Independent Assessments is being done to cut the costs of the scheme and will lead to reduced plan sizes. Moreover, it is generally perceived that there has been a lack of meaningful consultation with the community in designing this new process. Against this background, CYDA wished to explore experiences of children and young people and their families within the NDIS and perceptions of whether the proposed changes might improve the system.



Method

The survey was designed by CYDA staff in close consultation with the academic team.

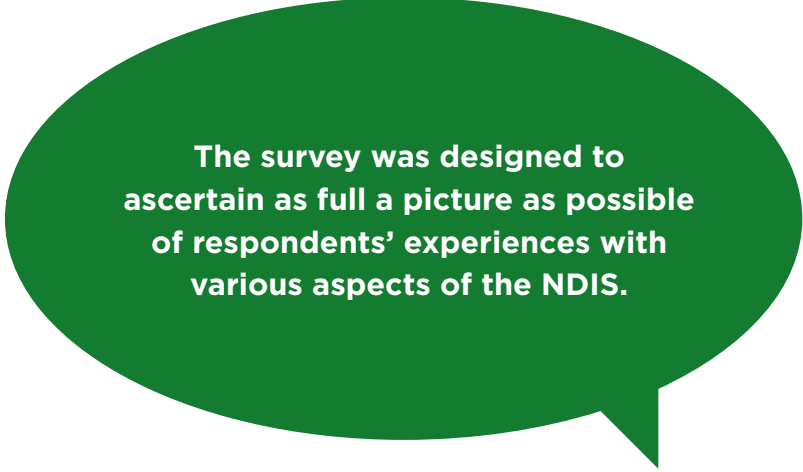
It was designed to ascertain as full a picture as possible of respondents' experiences with various aspects of the NDIS, beginning with a range of demographic questions. It then asked about experiences with access to the Scheme, and covered planning, funding levels, barriers to utilisation, and internal and external plan reviews. Questions comprised a series of yes/no or multiple choice items and two Likert scale items, with many opportunities for respondents to provide extra information in comment boxes.

Two free text items assessed overall experiences with the NDIS from different angles: asking about the best thing about the NDIS invited respondents to talk about ways the scheme had worked for them and improved the lives of children and young people and their families, and what they most valued about their participation. This was very important to the research team as we are interested in both highlighting the experiences of people whose lives have been improved by the NDIS, and considering how the scheme can work in this way for all participants. Asking about the worst thing likewise focused attention on the things people most dislike about their experiences of the NDIS (if anything), which allowed us to think about the relative weight respondents gave to problems they might encounter with scheme operation. Combined with free text comments from earlier questions on specific aspects of the NDIS experience, this allowed us to understand the full range of issues from respondents' perspectives, as well as the issues they considered to be most important.

Finally, the survey asked whether respondents had previously heard of the proposed introduction of Independent Assessments (with a link to information on the NDIS website for those who had not), and if so, how they had first been told. It asked whether participants thought Independent Assessments would be a positive change, and invited them to comment further.

There were two versions of the survey, both hosted on SurveyMonkey: one for children and young people talking about their own experiences, and one for families and carers responding on behalf of children and young people. The questions were worded slightly differently but were otherwise fully compatible with an aggregated analysis. The full survey can be found at Appendix 1.

The survey was open from 21 January to 21 February 2021. CYDA promoted the survey through newsletters and targeted emails to its membership of over 5,000 people, and also more broadly through Twitter, Facebook and Instagram. Quantitative data were analysed using SPSS, and qualitative data using inductive thematic analysis in NVivo. This research received ethics approval through the UNSW Human Research Advisory Panel, reference HC210197. In reporting data we indicate where free text comments are from young people and where they are parents and families. We have edited free text comments only to fix typographical errors.



The survey was designed to ascertain as full a picture as possible of respondents' experiences with various aspects of the NDIS.

Demographics of respondents

In this section we briefly break down the number and demographic characteristics of the sample.

In total 270 respondents took part in the survey. Of these respondents, 237 (88 per cent) were family members and 33 (12 per cent) were young people. As Table 1 shows, 58 per cent of children or young people were male and 38 per cent female.

Table 1: Gender of child or young person

	Number	%
Female	103	38
Male	156	58
Non-binary	5	2
Other	1	0
Prefer not to say	5	2
Total	270	

In addition to asking about the gender of the child or young person, in the case of family respondents we also asked for their gender. As Table 2 demonstrates, this elicited a stark response, with 94 per cent of respondents being female and just 4 per cent male.

Table 2: Gender of family respondent

	Number	%
Female	190	94
Male	9	4
Prefer not to say	3	1
Missing	35	
Total	237	

Respondents were located across the country, with representation from each state and territory. Most respondents came from Victoria (36%), Queensland (27%), and New South Wales (17%). There was also a mix of metropolitan (62%), regional (28%), rural (9%) and remote (2%) respondents.

Of the children and young people represented in the sample, 88 per cent were currently supported by the NDIS and a further 5 per cent accessing NDIS-funded early childhood intervention supports (Table 3). Only 7 per cent of our sample had not accessed support via the NDIS.

Table 3: NDIS participation of survey respondents

	Number	%
Funded NDIS participant	238	88
Accessing NDIS-funded early childhood intervention supports (ECEI)	16	5
Not sure if eligible	11	4
Applied for the NDIS but deemed ineligible	7	3
Eligible for NDIS but still waiting for a plan to be approved	1	0
Total	273*	

* 3 respondents were accessing ECEI and NDIS

Of those supported by the NDIS, Table 4 shows that 15 per cent were on their first NDIS plan and 16 per cent had five or more plans. Over half of our respondents were on their second or third plans. This demonstrates that our sample had significant experience of the scheme over time.

Table 4: How many NDIS plans

	Number	%
1 – on first NDIS plan	38	15
2	76	30
3	64	25
4	37	14
5	18	7
More than 5 NDIS plans	24	9
Missing	13	
Total	270	

In terms of how NDIS plans were managed, as Table 5 shows we see a propensity towards self-management within respondents. Just a small proportion were NDIA-managed or self-managed by the young person. A quarter were plan managed and over half were self-managed, with the remainder using a combination of types.

Table 5: How NDIS plan is managed

	Number	%
Self-managed by family member or carer	139	54
Plan managed	64	25
A combination of management types	28	11
Self-managed by young person	12	5
Managed by the NDIA	10	4
Unsure	4	2
Missing	14	
Total	270	

Findings

In this section we now move on to set out the findings of the survey. We start by exploring the positive experiences of the scheme, before moving on to the challenges and then to perceptions of Independent Assessments.

When the NDIS works well it can have profound impacts on the lives of individuals

In the comments provided to the survey it is clear that for some children and young people and their families, the NDIS was invaluable and had a significant impact on their lives. As one respondent told us:

"I'm eternally grateful for the NDIS. Without the NDIS I would be in my mid-twenties either in aged care, in hospital or homeless. NDIS has allowed me to live in my own home, drive my own car and live my life how I choose to independently. Absolutely life changing."

For this individual and for many others, the NDIS made a substantial contribution to people being able to live the type of life they want to. As another respondent explained:

"Flexibility. Autonomy. Able to be creative and live giving. Able to dream and make life wonderful. It's been a positive life changer for us."

Respondents were appreciative of financial relief and – relatedly – greater access to services and supports. This was sometimes expressed as services that

children and young people would not have been able to access otherwise, and sometimes as services that families would have needed to pay for out of their own pockets. When asked about the 'best thing' about the NDIS, 60 of the over 100 comments provided by respondents related to this theme, for example:

"Being able to access therapies, social activities and assistive technologies that we previously could not afford."

This was echoed by another parent who told us:

"The funds my son receives allows for him to access OT [occupational therapy] & Speech which we wouldn't have been able to afford. We have watched him grow in confidence & understanding. Our long term goal is for him to have a job of some sort when he gets older & with the continued support from NDIS this will be possible when he gets older. We will always be grateful & each year at my son's review I always say thank you."

"I'm eternally grateful for the NDIS. Without the NDIS I would be in my mid-twenties either in aged care, in hospital or homeless. NDIS has allowed me to live in my own home, drive my own car and live my life how I choose to independently. Absolutely life changing."

A less common theme (14 comments) was respondents' appreciation for self-management and the choice and control they could achieve through the NDIS, and a theme of similar strength was appreciation for benefits related to learning, development and community access.

For families with multiple children, the NDIS can be incredibly important in allowing for time and space with each child. This has been a particular challenge for many over the course of the last year within the context of the COVID-19 pandemic. One respondent explained:

"This year, having the funding to access a developmental educator, to write a behavioural support plan. Having sufficient funding now, to access support workers help him learn skills and give us much needed respite. This also allows us to have quality time to spend with our daughter."

Prior to the NDIS some families lived in constant fear that a change in their financial situation would have disastrous implications for their child. As one respondent explained:

"Peace of mind. If our financial planning falls apart I take comfort knowing my son will have support, especially after our deaths. I also take comfort in knowing our friends with similar disabilities aren't struggling financially to support their kids the way many used to before NDIS."

As this quote demonstrates, the NDIS has for some already overcome equity issues. This funding is not just important in terms of providing services, it also allows children and young people to engage with the community, which in turn can have an important role in shaping public perceptions around people with disability. As a parent told us:

"[The] NDIS is an amazing support without it there is no way we could have afforded services. It has enabled community access and changed the way a lot of people think about disability."



The fact that the Australian community has chosen to invest in the NDIS has in itself made children and young people with disability and their families feel less alone and more visible, heard and valued.

Another respondent suggested that the very existence of the NDIS:

"...sends an important signal about our community valuing people with disabilities."

The fact that the Australian community has chosen to invest in the NDIS has in itself made children and young people with disability and their families feel less alone and more visible, heard and valued.

Overall, the NDIS is a truly valuable resource for many of those who access it. If this could be the experience for all those who access it, then this would go a long way in supporting Australia to realise its commitments under the Convention on the Rights of Persons with Disabilities.

At the moment the NDIS doesn't work for everyone

While the NDIS works well for many children and young people and their families, unfortunately this is not the case for everybody. While as described above many of the responses to the 'best thing' about the NDIS had a fairly clear theme (access to services and financial relief), respondents' feelings about the 'worst thing' were much more varied.

The strongest theme related to confusion, complexity and administrative burden, with 33 comments about aspects of the system that confuse and overwhelm parents, carers and children and young people – such as not understanding how the system works; not knowing what services and funding they can ask for; and the time, effort and skills needed to navigate the system. There were also 31 comments relating to problems with NDIA personnel and Local Area Coordinators (LACs), for example perceptions of poor training and bias, adversarial behaviour, high turnover, and lack of understanding of disability. Thirdly, 21 comments about the 'worst thing' related to not being granted enough funding, variability in funding, or stress about having funding taken away. Other themes related to planning and review processes, lack of flexibility (e.g. in funding categories), and transparency and accountability.

For some the NDIS is highly stressful and uncertain, as one respondent explains:

"It has been anxiety and stress provoking at times due to unclear rules and regulations on what you can spend funds on. There is also little control on what service providers can force you to sign when wanting to use their services which could mean you are locked into a certain spend with them even if you decide not to continue with them. And the stress every plan renewal brings is enormous as the horror stories of people getting their funds cut tremendously is very worrying."

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"The constant stress of having to fight for funding, having people who have no idea about what children with disabilities and [their] families go through, being told things like "that's parental responsibility" when we explain the needs of our children, when if your child didn't have a disability there would be no need for the support recommended by therapists. Putting people with disabilities in "boxes"."

Such experiences were echoed by others, with one parent carer explaining:

"The constant stress of having to fight for funding, having people who have no idea about what children with disabilities and [their] families go through, being told things like "that's parental responsibility" when we explain the needs of our children, when if your child didn't have a disability there would be no need for the support recommended by therapists. Putting people with disabilities in "boxes"."

One further respondent summarised the review process as:

"A time consuming, exhausting nightmare, ending in tears. Not what was promised in 2012!"



Another respondent also noted a lack of consistency and continuity in processes:

“The reviews, the uncertainty of what funds she will have when the next plan comes in. The stress of plan reviews. Trying to explain to my daughter that she could do things before but now we don’t have the funding to have those same supports, she doesn’t understand. Also, NDIS is not at all black and white, it has so many grey areas, and this is causing everyone you speak to e.g. support coordinator, LAC, NDIS phone line, plan manager, delegates, all have very different answers about things.”

Some respondents commented that with successive plans these issues get easier as you learn to navigate the system:

“The scheme is unwieldy and intimidating at first contact. Only after a couple of plans do you come to grips with it and see the possibilities it opens up.”

One respondent summed up their review experience:

“It was hell ... The process is soul destroying and it took everything I had to survive it. I think I have PTSD [Post Traumatic Stress Disorder] the thought of the next review makes me cry, I feel nauseous. I know for my daughter’s sake I will dig deep and do whatever it takes but that doesn’t mean it won’t take its toll.”

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There must be a better way. I don’t mean to make it sound this is about me, it’s not it’s for my daughter but NDIS needs to come up with a better way as I don’t think destroying parents capacity is helpful to anyone. I think advocacy needs to be increased so we could get external help for these daunting times.”

We next go on to outline some of the challenges that were reported ranging from the application process, planning processes, funding allocated and barriers to using services and supports.

Challenges with access

Nearly 40 per cent of our respondents experienced challenges with the application process to the NDIS, as shown in Table 6. In free text comments some respondents elaborated on some of these issues. A substantial proportion of these comments indicated significant delays in access processes; one respondent described:

“A very long wait time.”

Another commented:

“It took 17 months from applying to have a plan.”

For some, the process was not only long but uncertain, not knowing what was coming next and having to respond to things at short notice:

“Lengthy process with little idea of progress. No information and then a “hurry up and wait” mentality.”

Interestingly, rather than decreasing over time, for our sample the challenges with applying for the NDIS appear to be more significant with more recent applicants, despite the Participant Service Guarantee recommended by the Tune Review and implemented by the NDIA (see Figure 1).

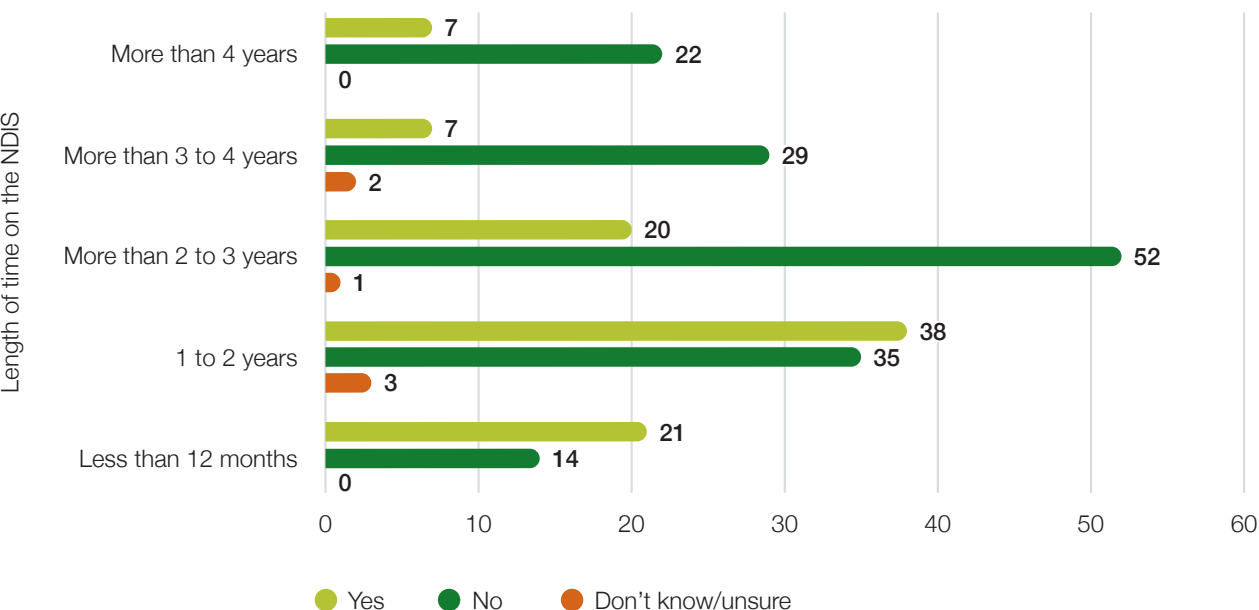
A chi square test revealed that respondents who had applied over the past two years were more likely to have experienced challenges with the application process than those who had been on the scheme more than two years, and these differences were statistically significant.

Table 6: Respondents experiencing challenges with the application process

	Number	%
Yes	103	38
No	154	57
Unsure	13	5
Total	270	

Figure 1: Respondents experiencing challenges with the application process by length of time as NDIS participants

Did you experience any challenges in applying for the NDIS?



One of the access challenges families face is in gathering evidence to prove they are eligible for the scheme and this often comes with a financial burden. As one respondent commented:

“Requested many assessments to be done costing large amounts of money.”

Another echoed this experience explaining:

“Extreme amount of documents required. Could not afford private OT assessment and hospital wouldn’t do it. Rejected by disability services until local MP assisted us.”

For some this was all the more problematic given they had been identified as having disability since early in their life. The impact of having to keep justifying this can be significant. As one young person explained:

“I am born disabled, so have been on this rodeo for a while. Most disabled people (in my experience) are exhausted enough, to be quite frank. So applying for NDIS is lengthy and painful. Furthermore, the medical trauma most disabled people experience makes it even harder to have the resilience to keep applying, chasing up NDIS, chasing up doctors, chasing up specialist, chasing up old records and new records.”

Some respondents were unsure about whether they would be eligible or not, but through extensive work could eventually secure access to the scheme. As one respondent explained:

“Told was ineligible a few times, paperwork I submitted was apparently not received, and there was limited communication to advise me if further info was required or not received. I spent hours on the phone to several different people trying to find how my application was progressing. It was a lengthy and exhaustive process.”

Others had concerns about how eligibility was determined. This respondent for example explains:

“Had several learning disabilities e.g. audio processing, dyslexia, anxiety but not until ASD was diagnosed did we get any help.”

“

“I am born disabled, so have been on this rodeo for a while. Most disabled people (in my experience) are exhausted enough, to be quite frank. So applying for NDIS is lengthy and painful. Furthermore, the medical trauma most disabled people experience makes it even harder to have the resilience to keep applying, chasing up NDIS, chasing up doctors, chasing up specialist, chasing up old records and new records.”

Others found the NDIS system confusing to access and reported mistakes being made by NDIA staff that were not easy to resolve. We have specified here how long ago these respondents applied. One respondent who had been accessing the scheme for 1–2 years told us:

“Age of child was wrong, somebody had written the wrong century, making the child 107 years old, instead of 7. This held up the plan and was only rectified by repeated phone calls by me.”

Others made comments such as:

“NDIS forgot to send out application forms, lost our application twice and it took around a year.” (on third plan, accessed NDIS more than 3–4 years)

“NDIS lost paperwork on x2 occasions. I needed to chase up to see where they had sent paperwork.” (on first plan, accessed NDIS less than 12 months)

Some reported that this was particularly challenging for people with disability:

“...process is difficult for disabled people to access, requires constant chasing down and phone calls and forms to fill out. Inaccessible when the caregiver is also disabled and no help offered to make it more accessible.” (on second plan, accessed NDIS 1–2 years)

Challenges with planning processes

Having secured access to the scheme, three quarters of our respondents had experienced challenges with planning processes (Table 7). A chi square test revealed no statistically significant differences according to length of time respondents had been accessing the scheme, although those who had been accessing the scheme longer were slightly more likely to report planning challenges (this is unsurprising as they have had a longer time over which to encounter difficulties).

The biggest theme in free text comments was that families did not always get what they needed because the planning process was poor. As one respondent commented:

“Professional reports were totally disregarded, leading to useless plan and s100 review, creating more work and stress.”

As in this case, such a situation often led to a review or appeal process to resolve this. Another respondent commented:

“The person who assessed for the second plan was rude, uncaring and didn’t understand my goals, even after my mum tried very hard to explain a number of times, so when the plan was approved it was not at all what we discussed so we had to have a review which took forever.”



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Table 7: Respondents experiencing challenges with the planning process

	Number	%
Yes	133	74
No	35	20
Unsure	10	6
Missing	92	
Total	270	

Many respondents felt that their planner did not understand their family’s situation and needs or disability more broadly:

“The planner has no idea of what challenges go with the disability and it’s hard to explain to them.”

This was echoed by another respondent who remarked:

“Planners having no clue about people with disabilities. Even if two people have the same diagnosis don’t mean they not the same support.”

Another respondent described:

“NDIS planner had my primary disability incorrect. Through a FOI [Freedom of Information] request I also found out that NDIS planner had incorrect information e.g. that I have a sister who provides informal care – I don’t have a sister.”

Incorrect information in plans can have significant impacts on children and their families, as the following quote indicates:

“One of my daughter’s plans had an admin error (staff didn’t input data rather typed random letters) which took about 6 weeks to rectify in which time my daughter had to put services on hold.”

Such delays can be particularly problematic given the importance of early intervention for some impairments.

Some Local Area Coordinators (LACs) were also perceived to have a poor understanding of disability:

“LAC is useless at communication needs of complex children and our plan has required multiple reviews every year since they were brought in.”

Such an experience could also leave individuals and families feeling like they had not been listened to and like they have no say in their plans. As one respondent commented:

“Untrained LACs making biased and unfair decisions based on personal opinions and judgements. Not representing the participant positively and treating the participant like dirt.”

This was echoed by another respondent who described their experience as:

“...condescending, awful questions on a surface pro, inaccessible participation. LACs were well meaning but really had no idea how young person could be active participant in the meeting.”

“

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Funding challenges, reviews and appeals

Nearly half of respondents (44 per cent) were satisfied with the amount of funding in their plan (Table 8), although nearly 40 per cent more were not satisfied and a number were unsure (17 per cent).

Table 8: Satisfaction with amount of NDIS funding

	Number	%
Yes	79	44
No	68	38
Unsure	31	17
Missing	92	
Total	270	

Regarding areas that plans are lacking, as Table 9 shows, the biggest areas identified are around personal support, therapy and capacity building supports, participating in the community and assistive technology. A further 16 per cent report needing help to use the NDIS and 14 per cent to help self-manage their budget. Just 13 per cent reported being satisfied with funding in all areas.

Table 9: Areas where plan is lacking

	Number	%
Personal support	98	41
Therapy and capacity building supports	91	38
Participating in the community	79	33
Assistive technology	76	32
Short term accommodation and assistance or respite	52	22
Support coordinator	39	16
Help to use the NDIS	38	16
Home modifications	36	15
Help to self-manage NDIS plans	33	14
I'm not sure	6	3
I am satisfied with funding in all areas	32	13

* Respondents could select no answers or multiple answers. Percentage expressed as proportion of respondents who were current NDIS participants (i.e. 238)

Many of the comments in the free text were concerned with the amount of funding and this being insufficient to gain the sorts of services and supports that are needed. Often families only received appropriate funding once they asked for a review:

“Always have to appeal in order to get correct supports.”

As Table 10 illustrates, over half of respondents had needed to ask for a review of their NDIS plan. Although longer term participants (i.e. those who had been accessing the scheme for more than two years) were more likely to have needed to ask for a review, a chi square test revealed this was not statistically significant, and about half of newer participants had also needed to ask for a review. One respondent commented:

“Even though we had comprehensive diagnosis with clear recommendations for care – we did not receive the funding for that care. It was not until I submitted a full risk assessment as part of an appeal that the Dr’s recommendations were fully funded.”

However, not everyone has a positive experience of plan review processes. As Table 11 indicates, only half of those who requested a review were happy with the outcome of this process. Many described the entire process as being incredibly stressful and frustrating:

“The supports are adequate but we have had to fight for them, once having to demand a review. This is extremely stressful for us as a family.”

Another respondent described the very real impact the review process had on their family and the implications of going without a fully funded plan:

“my family was left paying for therapies and supports that were reduced at an annual plan review...we were left paying around \$600 per week in therapy costs, and despite my calling the NDIS regularly to request updates and escalation of the plan review, at times distressed and in tears, one time I called and pleaded with them...I had \$1.70 left in the bank after therapy bills and groceries and Christmas was just around the corner, it took for my local MPs office to step in to get any progress.”



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In total, 14 respondents to our survey (5 per cent) indicated that they had escalated a review to the Administrative Appeals Tribunal (AAT). For these individuals and families, they had often gone through long and tough processes:

“Over the years we have had reviews, internal reviews, AAT cases and it has been stressful beyond what any person or family should ever have to experience.”

Others indicated they had wanted to pursue an appeal, but thought the process would be too challenging. As one respondent explained:

“People have told me I should appeal both plans, but I just don’t have the time and energy to fight.”



Table 10: Have you needed to ask for a review of your NDIS Plan?

	Number	%
Yes	129	54
No	101	42
Unsure	10	4
Missing	30	
Total	270	

Table 11: Were you happy with the outcome of your review?

	Number	%
Yes	63	50
No	34	27
Unsure	28	22
Missing	146	
Total	270	

Satisfaction with services and supports

Just under half (45 per cent) of respondents indicated that they are satisfied with services and support, with just under 40 per cent indicating they are not satisfied (Table 12). As Table 13 shows, respondents outlined a number of barriers to using services and supports. Amongst these barriers, more than half of respondents struggled to find suitable services and supports in their area and nearly half struggled to find workers that understand and empower the child or young person, both of which are different manifestations of thin markets. We illustrate these issues further below with comments from the free text.

Table 12: Satisfaction with services and supports

	Number	%
Yes	106	45
No	86	37
Unsure	43	18
Missing	35	
Total		

“

Amongst these barriers, more than half of respondents struggled to find suitable services and supports in their area and nearly half struggled to find workers that understand and empower the child or young person, both of which are different manifestations of thin markets.

Table 13: Barriers to use of services and supports

	Number	%
Finding suitable services and supports in my area	152	64
Finding workers that understand and empower the child or young person	112	47
Getting supports that work for children and young people	105	44
Finding out what services and supports are available and how to access them	104	44
Feeling safe and comfortable accessing the available supports	71	30
Accessibility barriers	39	16
Accessing supports that are culturally appropriate	10	4
I don't experience any barriers using my plan	25	11

* Respondents could select no answers or multiple answers. Percentage expressed as proportion of respondents who were current NDIS participants (i.e. 238)

The greatest barrier in using services and supports was in relation to what is often referred to as ‘thin markets’ in the literature. Thin markets can manifest in several different forms. The first challenge is lack of available services and supports. A number of respondents reported this as an issue and found they could not access services or supports as they either weren’t available or had significant waiting lists. As one respondent explains:

“Our area has long waiting lists and funding is cut when we can’t access therapies because of the long wait lists...”

This point was echoed by another who notes that this is especially the case for those professionals who are known to be good:

“In SA [South Australia] long waiting lists are ridiculous. When you find therapies/ therapists that are good their books are closed. SW [support workers] are always hit and miss leaving participants vulnerable.”

In this case this points to another dimension of thin markets – where services might be available but these are not necessarily ones that individuals or families want to purchase. Some respondents, however, found that self-management could be a good way to give more access to services than plan management offers:

“I have concluded that the NDIS budget is merely Monopoly money unless you can find a provider. We are self-managed and have more access than others who are plan managed but the ‘thin market’ situation here in Tasmania is a serious issue for all NDIS participants across the life span.”

Another strong theme in free text comments related to service providers being poor in quality or unreliable:

“Support worker agencies can function quite poorly- often disorganised, don’t let us know if a shift is cancelled, or can pull workers off shifts with little notice. Support workers can be very unreliable and cancel at very short notice with inadequate reasons e.g. too busy, want to go out with their boyfriend etc.”

A number of respondents reported struggling to find appropriate supports:

“To find good disability support workers to build a team to work with complex needs is like a needle in a haystack. There realistically isn’t enough DSW [disability support workers] trained in complex needs, particularly a child who is Non Verbal CCN/CSN.”

“

“In SA [South Australia] long waiting lists are ridiculous. When you find therapies/ therapists that are good their books are closed. SW [support workers] are always hit and miss leaving participants vulnerable.”

“

“In 5 years, I have only struck 2 support coordinators who are not money hungry criminals and/or completely inept at their job. The good ones are like hen’s teeth and frequently burnt out and thus leave the industry.”

As in this case, these issues were magnified where children and young people had challenging or complex needs:

“One of the biggest issues is accessing suitable support workers for young people who may exhibit violent and challenging behaviours at times. My son is non verbal so that also impacts upon my comfort level of who I trust to work with my son. We do not have any regular support workers at this stage.”

Others reported finding good supports only for them to burn out:

“In 5 years, I have only struck 2 support coordinators who are not money hungry criminals and/or completely inept at their job. The good ones are like hen’s teeth and frequently burnt out and thus leave the industry.”

Overall there is strong evidence of thin markets being experienced by our respondents.

Independent Assessments

We asked survey respondents whether or not they had heard of Independent Assessments and as Table 14 indicates, nearly three quarters had. Only 10 per cent had first heard about these changes through the NDIA, with nearly half finding out from social media and online groups and a further third through community or disability organisations (Table 15). This seems to suggest that, for our respondents at least, the NDIA has not been as successful in communicating these changes as other sources, which is clearly problematic in terms of a reform of this magnitude.

Table 14: Knowledge of intended IA roll-out

	Number	%
Yes	175	74
No	55	23
Unsure	6	3
Missing	34	
Total	270	



Only 10 per cent had first heard about these changes through the NDIA, with nearly half finding out from social media and online groups and a further third through community or disability organisations (Table 15). This seems to suggest that for, our respondents at least, the NDIA has not been as successful in communicating these changes as other sources, which is clearly problematic in terms of a reform of this magnitude.

Table 15: How respondents heard about intended IA roll-out

	Number	%
Social media, including online groups	66	48
Through community or disability organisations	40	29
From the NDIA directly	14	10
The news	8	6
Through a service provider	7	5
Peer or parent groups	3	2
Missing	131	
Total	270	

Of those who had heard about the intended roll-out of Independent Assessments, 80 per cent had a negative view, with just 6 per cent seeing this as a positive reform (Table 16).

We only received a few free text comments that were positive about the proposed reforms. One respondent remarked they were:

“Very happy, as I assume they will streamline the process.”

Another remarked,

“Great we won’t need reports every year but how independent is independent and how qualified are these people in the many different types of disability. What about fluctuating disability levels, e.g. mental health, level 1 ASD? Anything to take pressure off families and carers is good, I hope this will be an improvement.”

As this quote demonstrates, often respondents were unsure what the impacts would be due to a lack of information about the reforms and the anticipated associated changes.

Table 16: Attitudes to intended IA roll-out

	Number	%
Very positive change	5	3
Slightly positive change	5	3
Neither positive nor negative change	24	14
Slightly negative change	26	15
Very negative change	109	65
Missing	101	
Total	270	

Of the more negative perspectives on the reforms, there were a number of key themes. Firstly, respondents were concerned about the assessments being done by people who do not know the child or young person. From their experience of these kinds of interactions they are sure

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“...my 14 year old will not speak to a stranger, they will not speak at planning meetings, so I’m not sure how they expect answers. It has taken 2 years to get him to talk with current OT who just did a full functional assessment recently.”

that the child or young person will not engage with the individual or the process. As one parent carer explains:

“My son has multiple and significant disabilities, including severe anxiety. He will be completely unable to participate in a functional assessment with a stranger. Even in our own home, he hides or becomes aggressive if someone he doesn’t know enters our home or tries to approach him.”

Under the proposed policy, current NDIS participants will be forced to go through this process even though they have had functional analyses done in the past. Often there has been a careful process to build trust with professionals to facilitate this:

“...my 14 year old will not speak to a stranger, they will not speak at planning meetings, so I’m not sure how they expect answers. It has taken 2 years to get him to talk with current OT who just did a full functional assessment recently.”



Secondly, respondents were concerned that an assessor would not be able to grasp fully the functioning and needs of the child or young person within a short space of time. As one young person describes:

"I am very worried because my life needs cannot be assessed by a stranger in a few hours. I am worried that I won't get the continued funding I require to have a fulfilling life like I am having now."

As this quote illustrates, the implications of an incorrect assessment are significant in terms of the life supports of the individual and remaining engaged in their goals. These fears are further heightened for those with uncommon conditions or impairments:

"As someone with a rare and misunderstood disability, I am petrified about independent assessments. I dread the thought that someone who knows nothing or knows totally incorrect information about my disability and who only meets me for maybe 1 hour will determine the funding I get and therefore determine my life. As opposed to providers who specialise in my disability, I have known for years and know my needs. I think it is disgusting that the government is employing such a model on vulnerable, disabled people. Where is the choice and control?"

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Thirdly, for some children and young people there might be an instinct to ‘mask’ their support needs. Many children and young people find the process of answering ‘deficit’ questions about their lives highly traumatic so they may not give accurate responses. For these individuals they may not have yet come to terms with their identity as a disabled person and may just want to be seen in the same way as their peers. For others, considering the many things they cannot do may be highly stressful and cause significant anxiety. As this respondent describes:

“Not going to be valid for people with autism who mask. Increased mental stress”.

This comment was echoed by other respondents who queried whether there would be a role for parents to also contribute to these processes:

“Is there respect for a parent’s voice and observations in the IA process? My son is very skilled at masking his challenges. He would likely present better than his actual day to day capacity in a community setting. Masking is not widely discussed but a very real feature of some people’s experience of neurodiversity.”

Some parents were concerned that if they are asked to contribute, their children would be present and have to hear them talk about all the things they cannot do. Such a process would only reinforce a deficit mentality and leave them feeling negative about themselves:

“Having a stranger determine the needs and challenges of my child is very concerning. Also the idea that my daughter would be present during the plan meeting is also an issue. She hates people discussing her disabilities so this will be a big barrier for us and may see us need to leave the scheme.”

This was echoed by a young person who commented:

“I don’t want to talk to a stranger for assessment. Why can’t they use assessments from my therapists. I don’t want my mum to have to talk about me, in front of me, either.”

“

Many children and young people find the process of answering ‘deficit’ questions about their lives highly traumatic so they may not give accurate responses. For these individuals they may not have yet come to terms with their identity as a disabled person and may just want to be seen in the same way as their peers. For others, considering the many things they cannot do may be highly stressful and cause significant anxiety.

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Other respondents did not want to have conversations with assessors about their child without them present given that this process is supposed to be about *their* services and supports and not those of the parent. There was a general sense of confusion about what the Independent Assessment process would actually entail.

Fourthly, respondents are concerned that assessors might come on a day that is not typical, in the sense that they are having a very good or a very bad day. If this happens the assessor may not get a typical picture of what the child or young person is like on a day-to-day basis. As one respondent explained:

“Worried that the independent assessor will not be experienced in my son’s area of need. Also, that if he is having a “good” day, the assessor will not understand his real needs.”

One respondent linked together a number of these themes, explaining:

“It is totally unfair for him to be able to advocate for himself or to understand the implications of what he is saying or to even understand what is being asked. Results are likely to be highly inaccurate and a very negative experience all round. He does not need to have his face ‘rubbed in it’ and if having a ‘good’ day will seemingly need nothing at all.”

Finally, a number of respondents felt that this is a duplication of effort and an administrative burden. For those on the scheme who have already demonstrated through multiple assessment reports and processes that have cost money and time to produce, these will be discarded in favour of assessments by professionals who don’t know the child or young person. As one respondent described:

“The administrative burden is already very high. This will increase the burden, more people to deal with, more paperwork, more time with someone who doesn’t know about my young person’s needs. People with disabilities and their families are already time poor because of the extra time it takes to do simple things, going to appointments, self-advocacy, and trying to get additional support and accommodations for many daily activities. This is one more process that will likely involve lots of admin that we have to fit into an already busy schedule.”



“We have all sorts of tests and evaluations done by the professionals we work with and then we are supposed to have assessments done by an independent assessor as well. Sound like it’s duplicating time and money.”

While the case is made by the government that Independent Assessments will reduce the costs of gaining entry to the scheme, individuals will still be required to prove they are eligible for the scheme (i.e. have a significant and permanent disability) to receive an independent assessment. This was seen as a doubling up of effort by several respondents:

“We have all sorts of tests and evaluations done by the professionals we work with and then we are supposed to have assessments done by an independent assessor as well. Sound like it’s duplicating time and money.”

One parent carer summed up a number of these themes:

“Parents of already under so much pressure getting their children assessed, finding therapists. Having an independent assessment is yet again having to convince someone what your child’s needs are. It takes long term interaction with many of our children to understand where their needs are. Many of our children are very good at presenting better and disguising their actual needs. Which concerns me when someone who does not have a history with a client is making decisions for their needs. It also belittles the ability of the therapists our children are already seeing, for this very purpose. We already spend most of our lives visiting people and now NDIS want to add more.”

Overall, we discovered quite negative perspectives on Independent Assessments and little support for this reform direction.



Case study: The Independent Assessment Pilot experience

CYDA was able to speak with a parent of a child with disability who elected to take part in the Independent Assessment pilot. Margaret* shared her experience undertaking an Independent Assessment for her daughter Grace*:

Margaret's daughter Grace has a genetic disability and attends mainstream school. Grace has been an NDIS participant for several years and has had an overall positive NDIS experience after a difficult transition. Margaret, her husband Gary* and their family have built a strong multidisciplinary support circle and ecosystem around Grace to support her to live the life she chooses: "Our goal is for Grace to do what her older brother Thomas* does."

Margaret was contacted in late 2020 to participate in the Independent Assessment pilot. Margaret chose to participate in the pilot as Grace had not needed to complete functional assessments since beginning primary school and Margaret is beginning to think and plan for Grace's high school years. Margaret was keen to understand how Grace might be assessed in future functional assessments for high school, which impact the funding Grace receives for education supports.

There was very little information provided before the assessment took place. The assessment booking time was originally incorrect, as the booking office was located in a different time zone to Margaret and the assessor and did not factor in time differences. This was rectified prior to the appointment. The first name of the assessor who would complete the assessment was provided, but Margaret was not provided with the assessor's full name, gender, specialisation or qualifications.

It was requested that Margaret have access to a quiet separate space for the three hours the assessment would take. To do this, Margaret needed to use Grace's existing NDIS funding to book a support

worker for the full three hours. It was also stated that the assessor would need visual contact and a phone appointment would not be possible.

On the day, Margaret completed the assessment by video call on her iPad. Three separate assessment tools were completed during the independent assessment over the full three-hour period. Because multiple different assessment tools were completed, some questions were repeated: "By the middle of the second assessment, you feel like you're being tested on your answers because of the similar questions between assessment one and assessment two. Not because they were exactly the same, but I needed to answer similarly to make sure everything was in line."

Margaret describes the effect of this duplication of questions as "destabilising". She also acknowledged the severe impact that these assessments have on her as a parent: "The nature of assessments is that I have to talk about my child in a way that I absolutely hate. I have to do that to get the bare minimum for her."

Margaret set strong boundaries to ensure Grace's emotional health was prioritised during the day. The assessor met Grace early on in the assessment process, but most assessment and discussion occurred away from Grace in a separate room. Margaret knows from experience how frustrating Grace finds it to be discussed by strangers and chose to avoid this as much as possible. Being able to set this boundary meant the day and assessment had minimal emotional impact on Grace.

Margaret was told the assessment results would be used to create a draft plan for Grace and the report would be forwarded to the NDIA. She has had no contact from the assessor organisation or from the NDIA since completing the assessment and no follow-up feedback was requested or support offered. When reaching out to the assessor organisation to find out when she would receive

Grace's report, she was told to contact the NDIA. The NDIA had not responded to Margaret's email at time of writing.

Margaret found the whole experience "physically and emotionally draining" and is sceptical that the impending assessment results will accurately describe her child. She said: "Based on what they asked me, and based on what I know about planning processes and plan reviews, they don't have the full picture. Not medically – it's more that they don't have a full picture of her full capacity and functional needs."

Margaret highlighted several serious issues with the functional assessments in regard to her child:

- The functional assessment questions were developed before the widespread use of iPads and do not seem to account very well for the use of assistive technology, particularly as an alternative to traditional methods (e.g. Apple Pay as a replacement for the use of cash).
- For young children, many of their skills and experiences are dependent on what their families choose to expose them to or develop at different life points – e.g. different families will have different boundaries on children walking to the park or the corner shop independently according to age. This is not necessarily a reflection on child development.
- The assessments do not discuss a child or young person's life at school – a significant amount of time is spent in the classroom.
- The assessments "only ask about a point in time as opposed to goals, expectations or the realities of lifelong, permanent disabilities". All assessments compared Grace against a typically developing child and did not consider what developmental focus and goals Margaret and Grace actually have.
- The questions asked did not take into account individual experiences, demographics, and goals. One question revolved around rating the child or young person's ability to handle cash. Margaret's whole family favours cashless payments – something not uncommon since the outbreak of COVID-19. This meant that evaluating Grace's ability to handle



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money was not necessarily appropriate or reflective of her skillset. Margaret says, "Our decisions of what to pursue and the experiences she's exposed to are not reflected in her functional assessment."

- The functional assessments do not ask about a child or young person's individual circumstances and apply these as context – factors such as metro, regional or rural location, family dynamic, languages spoken, or birth order affect what children and young people have access to and their subsequent skill development. One assessment asked about activities in the community and whether doing more would be ideal but did not ask whether more activities were available and accessible to do.
- In addition to questions about Grace, Margaret was asked many questions about how long is spent doing specific activities for Grace, including cleaning and personal care: "It assumes I'm aware of how long I spend doing something for my child and if it is because of her disability – a heavy mental load."

* Names have been changed.

Discussion

In making the case for the establishment of the NDIS, it was argued that disability services were underfunded, inflexible and built around the needs of the system, rather than of individuals (National People with Disabilities and Carer Council 2009). It had long been recognised that the quality of Australian disability services and outcomes for people with disability were poor, particularly when compared to other developed nations.

A study from the OECD found Australians ranked lowest in terms of quality of life for people with disability (OECD 2009). Against this background, the NDIS was a much needed and welcome reform promising to transform the lives of people with disability. As outlined in this report, for some this has been realised. When the NDIS works well it can be transformative and it can support children, young people and families to live the lives they want and achieve their goals. But as this report has also demonstrated, these benefits are not felt by all.

For some of our respondents the NDIS can be a highly stressful and problematic process to navigate. There are a variety of reasons for this, and challenges are experienced differently depending on the specific characteristics, contexts and goals of children and young people and their families.

In response to this survey we heard about challenges relating to various aspects of the NDIS including:

- The complicated nature of the scheme and its associated bureaucratic structures;
- Issues with accessing the scheme;
- Poor quality planners and plans with insufficient funding;
- Challenges of retrieving funds when the service chosen is not a good fit;
- Poor quality Local Area Coordinators;
- Stressful review processes;
- Long and complicated appeal processes around inappropriate plans; and,
- Thin markets, meaning children, young people and families can't purchase the services and supports they need.

No scheme can ever be perfect, and particularly a reform of this size, introduced as quickly as the NDIS has been, would have aspects that don't work well for some individuals and groups. Over the past seven years the NDIA has made a range of changes to the scheme and some of these have started to address problems with the scheme.

When the NDIS works well it can be transformative and it can support children, young people and families to live the lives they want and achieve their goals. But as this report has also demonstrated, these benefits are not felt by all.

It is well known, however, that the NDIS does have a number of inequities (see, for example, Warr et al. 2017, Carey et al. 2018, Green 2019, Cortese et al. 2020) and it is encouraging that the NDIS is planning to implement more reforms to address these.

However, it is difficult to see how the introduction of Independent Assessments would deal with many of the challenges our participants have experienced. As became clear through responses to survey questions about the ‘best thing’ and the ‘worst thing’, the aspect of the NDIS respondents clearly most appreciated was financial support and greater access to services (which were often linked), while the things respondents found most difficult were many and varied. Even on the issue of access to the scheme, with the introduction of Independent Assessments there would still be a requirement to demonstrate an individual meets the eligibility requirements, meaning that reports from medical professionals would still be needed.

Indeed, for some individuals, this process will become *more* onerous with the removal of access lists. Even *if* Independent Assessments did make plan allocations more fair (and there is significant evidence to suggest this will not be the case), participants will still face inequities in spending those funds. Data from the NDIA demonstrates that there are significantly different utilisation rates (the proportion of allocated budget spent) across the country. For example, the average utilisation rate for East Arnhem is just 33 per cent (National Disability Insurance Agency 2020e). While there are good reasons why utilisation rates will likely never be 100 per cent, there are significant areas throughout the country where these rates hover around the 60–70 per cent mark. Within areas it is also likely that there are low utilisation rates for some services where the market provision is weak.

The respondents to this survey were overwhelmingly clear that Independent Assessments are not a welcome reform and the prospect of their introduction is causing a lot of stress and worry for young people with disability and their families. The NDIS makes such an important difference for some children, young people and families



Even if Independent Assessments did make plan allocations more fair (and there is significant evidence to suggest this will not be the case), participants will still face inequities in spending those funds.

around the country. If improvements can continue to be made, then these benefits will be able to be shared with others. Yet it feels like a reform opportunity might be wasted through the introduction of Independent Assessments, which are an unpopular and flawed solution to the issue of inequity in the NDIS.

We welcome the recent announcement from Minister Reynolds putting the introduction of Independent Assessments on hold for now until the trial of these mechanisms has been completed. However, we would note that the trial will not provide the necessary data to make an informed decision about the impact of Independent Assessments. The approach that has been taken in their evaluation will not give evidence about their full impact (Dickinson, Kavanagh, and Carey 2021). As shown in Grace and Margaret’s story, they did not receive a copy of their assessment despite repeated requests. They received a survey to evaluate their experience of the process, but this is done without any idea about what judgements have been made about functional capacity or how this will impact the plan and budget of the NDIS participant. The evaluation will at best be able to make some judgements about the process of Independent Assessments but not its outcomes. For a change of this magnitude it is crucial that we have good evidence. We hope the Minister will listen to the voices of children and young people and their families set out in this report and take these into account in making decisions about the future of this scheme.



Conclusion

The NDIS is a world-leading scheme and for some is providing excellent and much needed supports. However, this is not the case for everyone and there are some significant inequities within the scheme.

Action is needed to attend to these inequities, but Independent Assessments are not the right answer. While the government says that Independent Assessments will make the scheme more consistent and fair, it is difficult to see how this is the case. They do not entirely remove the financial burdens associated with demonstrating eligibility for the scheme; potential participants will still be required to prove a permanent disability in order to go through the Independent Assessment process.

Moreover, the process of demonstrating eligibility will be more burdensome for those who would currently gain entry via Access Lists. Those who have already demonstrated a lifelong disability will be required to go through this process, despite the extensive information the NDIA already holds on these individuals.

Rather than being more fair and consistent there are well founded concerns that assessments done by a stranger unknown to children and young people and their families will provide an inaccurate picture of their lives and abilities and this will lead to inappropriate assessments and unsuitable funding systems that cannot be appealed.

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This is not at all in line with the Tune Review, which recognised the limitations of functional assessments and made provision for discretion in order to ensure that funding decisions would be in line with the NDIS Act's aim to uphold and facilitate human rights. Further, the proposed reforms will do nothing to deal with issues in relation to poor planning, local area coordination, or the many challenges experienced with respect to thin markets.

We hope the Federal government listens to the voices in this report and is able to recognise that Independent Assessments are a flawed solution. Ultimately we hope that this opportunity for reform is not wasted and there can be a process of co-design to ensure that everyone who accesses the NDIS is able to benefit from it.

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Appendix 1: Survey questions

Note: Survey version below was designed for children and young people with disability to complete about their own experiences. The survey for family members and carers included the same questions, but worded differently. This appendix only lists questions and changes relevant to the results described in this report (some items were excluded from analysis as they will be reported elsewhere).

About you:

- I am a family member of a child or young person with disability
- I am a young person with disability
- Other (please specify)

What is your age?

- 0–3 years
- 4–6 years
- 7–9 years
- 10–12 years
- 13–15 years
- 18–18 years
- 18–25 years
- 25+

What is your gender?

- Female
- Male
- Non-binary
- Prefer not to say
- Other (please specify)

Are you of Aboriginal or Torres Strait Islander background?

- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, Aboriginal and Torres Strait Islander
- No
- Prefer not to say

What state or territory do you live in? (*List of Australian states and territories*)

What type of area do you live in?

- Metropolitan area
- Regional area
- Rural area
- Remote area

Are you currently attending or doing any of the following activities? You can choose more than one.

- Early Childhood Education and Care (e.g. childcare, preschool, kindergarten)
- Primary School – special school
- Primary School – regular or ‘mainstream’ school
- Dual enrolment between primary mainstream and special school
- Secondary School – special school
- Secondary School – regular or ‘mainstream’ school
- Home school
- Day program
- Australian Disability Employment (e.g. supported workplace)
- Open employment
- TAFE
- University
- Not in education or work
- Other (please specify)

Are you current accessing the NDIS?

- Funded NDIS participant
- Accessing NDIS-funded early childhood intervention supports
- Eligible for NDIS but still waiting for a plan to be approved
- Not sure if eligible
- Applied for the NDIS but deemed ineligible
- Other (please specify)

APPENDIX 1: SURVEY QUESTIONS

If you are an NDIS participant, how long have you been accessing the NDIS?

- Less than 12 months
- 1–2 years
- More than 2–3 years
- More than 3–4 years
- More than 4 years
- Other (please specify)

How many NDIS plans have you had so far?

- 1 – on first NDIS plan
- 2
- 3
- 4
- 5
- More than 5 NDIS plans
- Other (please specify)

If you are an NDIS participant, how is your plan managed?

- Managed by the NDIA
- Plan managed
- Self-managed by me
- Self-managed by someone other than me (e.g. my parent or caregiver)
- A combination of management types
- Unsure

If you would like to tell us more, please leave a comment below.

Did you experience any challenges in applying for the NDIS?

- Yes
- No
- Unsure

Did you experience any challenges during the NDIS planning process?

- Yes
- No
- Unsure

Why or why not?

Are you satisfied with the amount of NDIS funding in your plan?

- Yes
- No
- Unsure

Why or why not?

Are you satisfied with the supports and services you receive under the NDIS?

- Yes
- No
- Unsure

If you would like to add to your answer above, please leave a comment below.

Are there specific areas in which you feel your plan is lacking? You can choose more than one.

- Personal support (support workers, accessing the community)
- Therapy and capacity building supports
- Assistive technology
- Home modifications
- Participating in the community such as events or peer networks
- Support coordinator
- Short Term Accommodation and Assistance or respite
- Help to use the NDIS
- Help to self-manage NDIS plans
- I'm not sure
- I am satisfied with the funding in the areas of my plan
- Other (please specify)

Do you experience any barriers to using your NDIS plan?
You can choose more than one.

- Finding suitable services and supports in my area
- Getting supports that work for me as a young person
- Finding out what services and supports are available and how to access them
- Accessing supports that are culturally appropriate
- Accessibility barriers
- Finding workers that understand me and empower me
- Feeling safe and comfortable accessing the available supports
- I don't experience barriers using my NDIS plan
- Other (please specify)

If you would like to tell us more, please leave a comment below.

Have you needed to ask for a review of your NDIS plan?
This includes unscheduled reviews, reviews of a reviewable decision (RORD), or change of circumstances (COC) reviews.

- Yes
- No
- Don't know/unsure

If you would like to, please tell us more about your experience.

Were you happy with the outcome of your review?

- Yes
- No
- Don't know / unsure

If so, what happened?

Have you ever needed to escalate a review to the Administrative Appeals Tribunal (AAT)?

- Yes
- No
- Don't know/unsure

What has been the best thing about the NDIS from your perspective?

What has been the worst thing about the NDIS from your perspective?

Are you aware the NDIS is planning to introduce Independent Assessments? More information can be found on the NDIS website. <https://www.ndis.gov.au/participants/independent-assessments>

- Yes
- No
- Unsure
- Other (please specify)

If you know about Independent Assessments, how did you find out?

- From the National Disability Insurance Agency (NDIA) directly
- I have had an NDIS Independent Assessment
- Through community or disability groups or organisations
- Through a service provider
- Social media, including online groups
- Peer groups
- The news

What are your thoughts on the upcoming introduction of Independent Assessments?

- Very positive change to the NDIS
- Slightly positive change to the NDIS
- Neither positive nor negative change to the NDIS
- Slightly negative change to the NDIS
- Very negative change to the NDIS

If you want to, please tell us more about your thoughts on independent assessments.

Is there anything else you would like to tell us about your NDIS experience?

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