

**Submission to the Joint Standing Committee
on the National Disability Insurance Scheme
Inquiry into independent assessments under the NDIS**

**Children and Young People with Disability Australia
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Acknowledgements:

Children and Young People with Disability Australia 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.

Contents

Recommendations.....	2
Introduction.....	3
Lack of community engagement and genuine consultation	5
Absence of an evidentiary basis for the reforms.....	10
<i>Serious concerns about the current independent assessment pilot</i>	10
<i>CASE STUDY: Grace’s pilot Independent Assessment</i>	11
Failure to address existing equity issues and barriers	13
<i>Current equity issues in the access process</i>	13
<i>Current equity issues in plan implementation</i>	13
<i>Equity risks through independent assessments</i>	15
Undermining of individuals’ lived experience, goals, and aspirations	16
<i>Undermining people’s agency and creating robo-budgets</i>	16
<i>Safeguards and review mechanisms are limited</i>	18
Lack of consideration for the broader NDIS ecosystem.....	20
<i>Workforce challenges</i>	20
<i>Lack of clarity around the role of support coordinators and LACs</i>	20
Consider the appropriateness of independent assessments for young children	22
Appendix A. Demographic data for 2021 survey respondents.....	24
Appendix B: Comments from family members, caregivers and young people on independent assessments.....	27

Recommendations

- Immediately halt the roll-out of the independent assessment program as currently proposed.
- Commission an independent evaluation to be undertaken of the current independent assessment pilot, and publish and listen to its findings.
- Consider and respond to the serious concerns being raised by people with disability, families/caregivers, and representative organisations about the proposed changes.
- Provide genuine consultation and engagement mechanisms for people with disability, and families and caregivers, to learn about the Agency's proposed changes and provide feedback.
- Undertake specific consultation and engagement with children and young people with disability supported by their representative organisations, recognising they are the majority of NDIS participants.
- Plan and implement any large changes to the NDIS through a meaningful co-design process with people with disability, including people under the age of 25 years.
- Work with people with disability and representative organisations to design and trial evidence-informed approaches to addressing existing inequities to accessing and utilising the NDIS.

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion
- Creating equitable life pathways and opportunities
- Leading change in community attitudes and aspirations
- Supporting young people to take control
- Calling out discrimination, abuse, and neglect.

This submission is in response to the Joint Standing Committee on the National Disability Insurance Scheme's (NDIS) inquiry into independent assessments under the NDIS.

Children and young people make up more than half (57 per cent) of all NDIS participants.¹ While acknowledging that the world-first and still relatively new Scheme has many areas for ongoing development and improvement, we hear from our community that when the NDIS is good – it's great. It has allowed many children and young people to access supports they need to participate in activities and communities in line with their interests and aspirations. While improvements are needed to improve the Scheme, the introduction of independent assessments are retrograde and will actually reinforce and exacerbate existing inequalities.

Both CYDA and the broader disability community are deeply concerned with the proposed introduction of independent assessments and the changes the National Disability Insurance Agency (NDIA) is proposing to NDIS access and planning processes. As such, CYDA has contributed to a [disability sector joint statement](#) which opposes the reform in its current form. For a Scheme that has only recently achieved full transition, these dramatic reforms appear rushed and opaque, and there is a lack of clear evidentiary basis or genuine engagement with the communities who will feel their impacts.

CYDA conducted two surveys through January and February 2021 to understand the direct experiences of children and young people with the NDIS: one for families and caregivers of children and young people and the other for young people directly. Additionally, we held two briefing/Q&A sessions on the proposed changes in February 2021. Data from our surveys, and the feedback and questions raised by parents, caregivers and young people during the briefing sessions, have been used to inform this submission and its recommendations.²

¹ As at September 2020; NDIA. (2020). *Explore data*. Available at <https://data.ndis.gov.au/explore-data>

² As at 9am on 22 February 2021, we had received 206 responses to our families/caregivers survey, and 29 responses from young people with disability. Quantitative data from the families/caregivers survey has been used throughout this paper. Due to the small sample size, we have used qualitative data only from the young people survey. Demographic data for our respondents is detailed in Appendix A.

Worryingly, our survey data show:

- Almost one in four respondents reported being unaware of the introduction of independent assessments
- Only 10 per cent reported finding out about independent assessments directly from the NDIS. The majority said they found out through social media or through disability groups and organisations.
- High levels of concern about the proposed changes. Eighty per cent of respondents feel that the introduction of independent assessments will be a negative change to the NDIS.

The issues identified by CYDA and our community members include minimal activities and planning being undertaken to inform the community of the changes, little consultation or seeking informed feedback from the community, and the absence of a rigorous research and evaluation process before proceeding with decision-making. We consider the proposed reforms also fail to properly address the underlying reasons for current Scheme inequities, and introduce unjust and unreasonable mechanisms that will limit the ability for people with disability to have a say in the decisions that impact their lives.

As such, this submission emphasises that the consultation, research, and evaluation processes behind the reforms are inadequate and must be immediately rectified before proceeding with any changes. The submission also outlines the risks and unintended consequences of the reforms, as well where the proposed changes miss the mark or leave the actual underlying issues in access and planning unaddressed.

It is also crucial that the NDIA provides people with disability – ultimately, the group who the changes will most impact – with clear, appropriate, and timely information, delivered in a way that meets their communication preferences and needs, so they can understand the proposed changes and be informed when engaging with genuine consultation processes.

Lack of community engagement and genuine consultation

The introduction of independent assessments is arguably the biggest fundamental change to the NDIS since its introduction, with the proposed changes having a direct impact on all current and prospective participants of the Scheme. Despite the significance of the proposed changes, the NDIA has conducted minimal consultation and engagement with people with disability, families/caregivers, or their representative organisations – the community that the changes will most affect.

The Tune Review did conduct extensive consultation and recommended³:

7. *The NDIS Act is amended to:*

- a) *allow evidence provided to the NDIA about a prospective participant or participant to be used for multiple purposes under the NDIS Act, including access, planning and plan review processes*
- b) *provide discretionary powers for the NDIA to require a prospective participant or participant undergo an assessment for the purposes of decision-making under the NDIS Act, using NDIA-approved providers and in a form set by the NDIA.*

However, recommending discretionary powers is very different to the compulsion of all participants to undergo an assessment for access, planning and review processes. While the Minister and the NDIA have said they have consulted with the community, the reform they have put forward misrepresents and expands on the recommendation of the Tune Review – a review with a genuine consultation process – to now include that independent assessments will be used for all participants, all of the time. The reforms put forward by the NDIA also fail to acknowledge the caution about independent assessments that were noted by both the Tune Review and the original Productivity Commission inquiry report.

Regarding the use of independent assessments for current participants, the Tune Review found it to be “a reasonable expectation that participants might need to undertake further assessments from time to time to ensure their plans remain fit for purpose.”⁴ However, Mr Tune took care to situate this comment within the context of broader problems with NDIS planning processes, observing “some consultation feedback indicated that some planners are either not fully considering the reports participants provide or are not sufficiently taking into account the recommendations of experts.”⁵ The report made no findings about the need for re-assessment to be compulsory, or mandated, or that plan flexibility would be conditional on receiving an independent assessment. The NDIA already has the capacity to request further assessments if needed.

The assessment of support needs was also examined in detail by the Productivity Commission in its initial inquiry into disability care and support⁶ – the blueprint for the NDIS. The inquiry report discussed the importance of independent functional assessments and specifically noted participants’ concerns about assessors not having detailed knowledge of the individual and their circumstances. The report suggested that “while the individual undertaking assessments would be independent, it would [be] important to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and

³ Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee.*, p. 67

⁴ *ibid.*, p.61

⁵ *ibid.*, p. 62

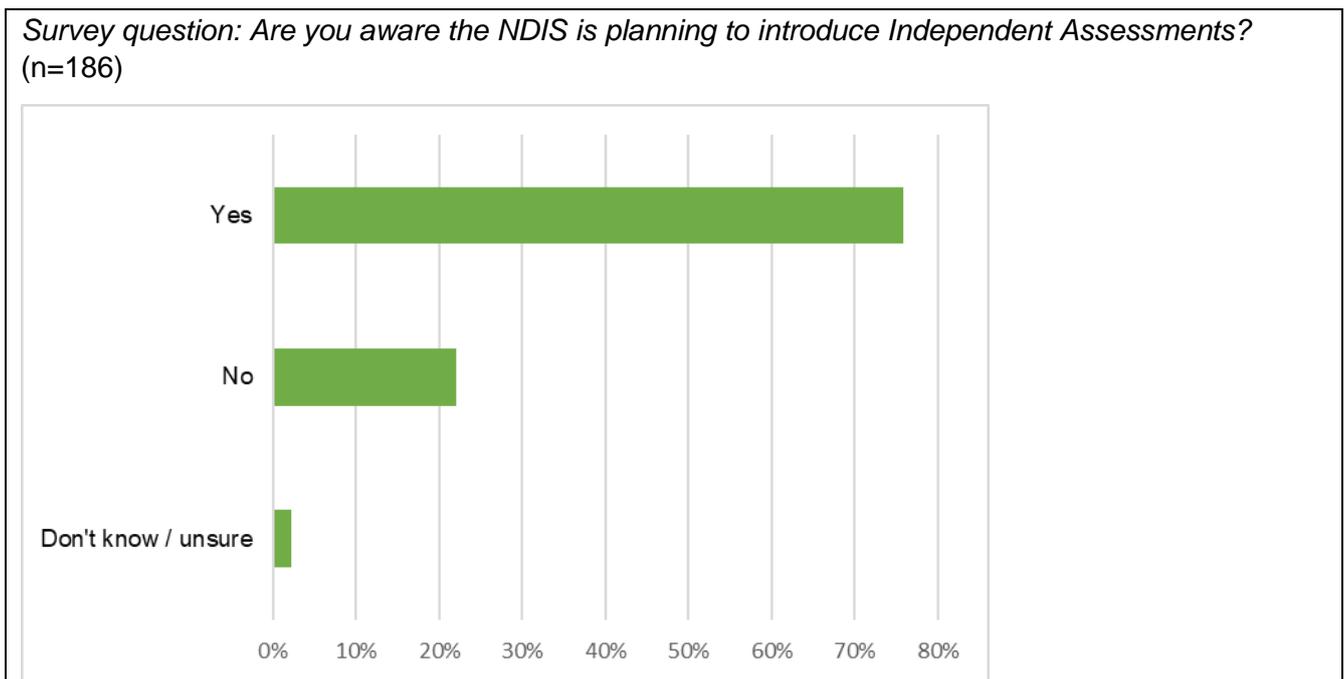
⁶ Productivity Commission. (2011). *Disability Care and Support*, Report no. 54.

support needs of the individual, they might include family members, carers and direct support professionals. Moreover, the assessment process would draw upon existing medical reports.”⁷

There has been little consultation on the proposed methodology for independent assessments by the NDIA, despite claims to the contrary by the Minister⁸ and the NDIA. CYDA and other disability representative organisations were provided with a ‘fait accompli’ position after the NDIA had decided on the method, tools and compulsion for all participants to undergo and were presented with a set of ‘not-negotiables’. Since late last year, we have been trying to advise the NDIA of the challenges and problems of their proposed approach to no avail.

In our recent NDIS surveys we asked our community whether they had heard of the proposed independent assessments approach, and if so, how they had heard about it. Worryingly, given they are slated to be compulsory, almost a quarter of our respondents (22 per cent) reported they had not heard of the proposed reforms (Figure 1). For those who said they had heard of the proposals (76 per cent), only 10 per cent reported learning about the new approach directly from the NDIA. Almost half of respondents reported finding out about the changes through social media, including online groups, with an additional 29 per cent finding out through community or disability groups/organisations (Figure 2).

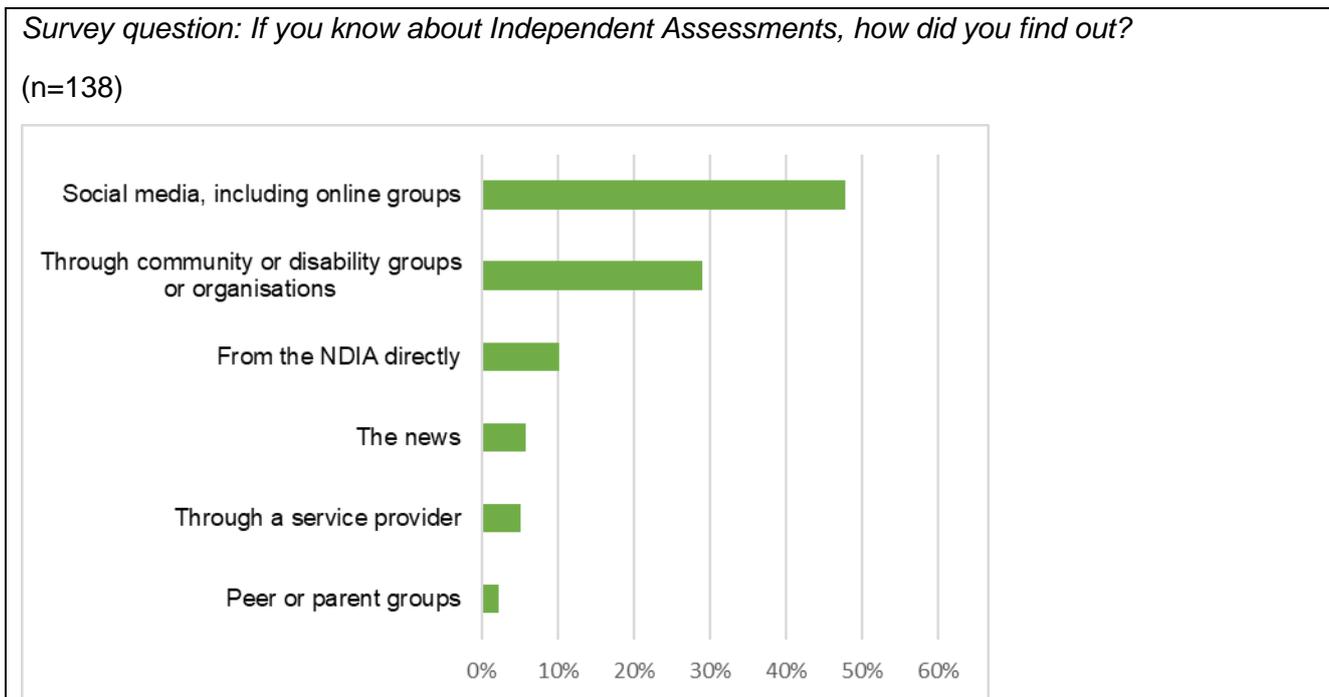
Figure 1. Respondents’ awareness of the proposed introduction of independent assessments



⁷ Productivity Commission. (2011). *Disability Care and Support*, Report no. 54, Volume 1, p.327.

⁸ Henriques-Gomes, L. (2021, March 7). Backlash grows over 'independent assessments' plan for disability scheme. *The Guardian*. [Backlash grows over 'independent assessments' plan for disability scheme | National disability insurance scheme | The Guardian](#)

Figure 2. How respondents found out about the proposed introduction of independent assessments



The respondents who were aware of independent assessments were then asked about their thoughts on them, with an overwhelming majority (80 per cent) responding that they thought it was a slightly or very negative change to the NDIS. Only 7 per cent of our respondents reported thinking the introduction of independent assessments would bring a slight or significant positive change to the NDIS, with 14 per cent undecided (Figure 3).

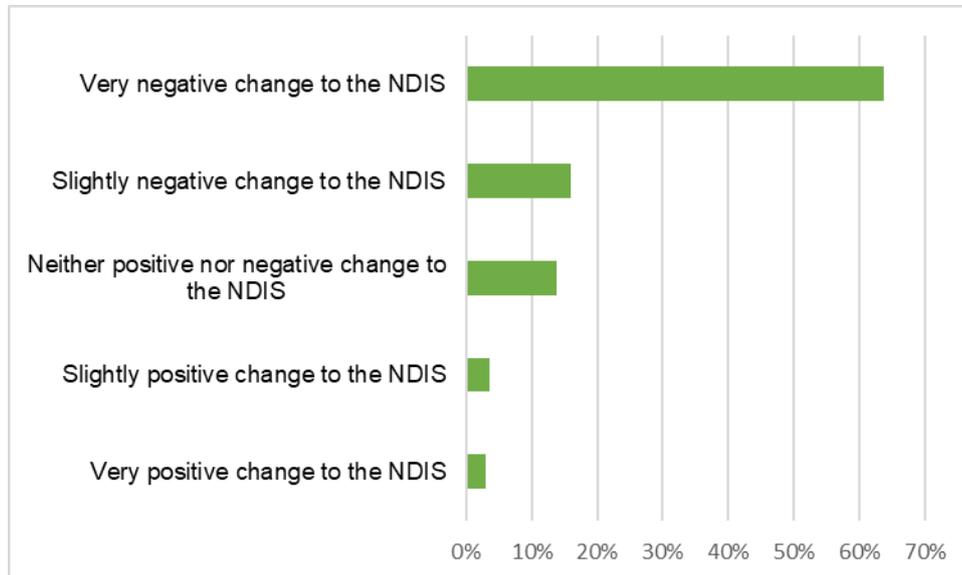
This is consistent with findings from People with Disability Australia’s 2020 survey of its members, which found around three quarters of respondents believe the rapid roll-out of independent assessments is a bad or extremely bad idea.⁹ Half of the PWDA survey respondents reported feeling overwhelmed by the proposals, and over 60 per cent said they feel defeated.

⁹ People with Disability Australia (2021). *Raw Data, Real Insights: Voices and views of people with disability on the Australian Government’s plans for rapid rollout of NDIS independent assessments*. Provided as a submission to this consultation.

Figure 3. Respondents' views on the proposed introduction of independent assessments

Survey question: *What are your thoughts on the upcoming introduction of Independent Assessments?*

(n=138)



The high level of concern in the community is reflected in the open text responses we received in CYDA's surveys:

"I am [a] capable and proactive parent of children with disability. I have built strong relationships with therapists doctors and providers over many years, including before our access to NDIS. I find it inappropriate and demeaning that the NDIA believes they have staff who could possibly know what is required to care for and raise my children with disability. I would even go so far as to say it discriminates against the rights of my children to have an unknown assessor make decisions about their care. In my rural area, we suffer terribly with a lack of sufficient therapists, supports and knowledgeable Local Area Co-ordinators, I do not believe that the NDIA will be able to provide sufficiently qualified assessors and I believe the employment of assessors uses funding that should rightfully be used by people living with disability." - Family member/caregiver of a child

"I worry about another business being involved in decision making, where their priority might be on numbers or outputs rather than individuals and their families. My child has been regularly assessed and reviewed since he was born, he doesn't like assessments and often refuses to participate meaning the process needs to be broken down over a number of sessions, often taking weeks (or sometimes months) to complete." - Family member/caregiver of a child

More comments from family members, caregivers and young people on the proposed introduction of independent assessments are included in Appendix B.

Despite the clear and warranted concerns of people with disability and their families and caregivers, the community consultation processes offered by the NDIA have been narrow and feel disingenuous, which risks exacerbating existing community distrust of the Agency. While the NDIA

recently invited the community to provide feedback on consultation papers¹⁰, the questions in the papers failed to ask individuals their thoughts and opinions on independent assessments and the major aspects of the service reforms – some of which require legislative change – instead, posing questions that assume the changes are set in stone. This is consistent with the messaging released by the Agency and the Australian Government in media and online.

The young people and family members and caregivers we have spoken to are deeply concerned with the NDIA's lack of transparency and clarification around the application of independent assessments. Calls for further information about the process are being echoed by many individuals and peak bodies/representative organisations, including the national allied health peak organisation (see next section).

¹⁰ NDIS. (2020). *Consultation paper: Access and Eligibility Policy with independent assessments*. Available at <https://www.ndis.gov.au/media/2874/download>; NDIS. (2020). *Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility*. Available at <https://www.ndis.gov.au/media/2875/download>

Absence of an evidentiary basis for the reforms

While assessment of functional capacity can be an important element to understand a person's needs and guide the provision of appropriate supports,¹¹ there is still much unknown about how to do this in a way that is reliable, valid and fair for all groups. To date, the proposed NDIS independent assessment program is untried and untested, but it will affect the lives of many hundreds of thousands of people.

The suite of assessment tools the NDIA has chosen have been stated to be based on best-practice and are focused on clinical and functional issues, with different ones used for different age groups. However, they were not designed to decide appropriate funding. This is an untested application and no other disability system in the world uses this approach.¹²

The independent assessment program is purported to deliver a fair and appropriate assessment of people of all ages, all disability-types, all genders, across all metropolitan, regional and rural regions in Australia, while meeting different cultural needs. As far as CYDA can gauge, it will be one of the first times in the world that the selected tools – which are designed to be used for screening and assessing functional capacity – will be used to calculate and allocate funding for supports.

The allied health professions peak body, Allied Health Professions Australia (AHPA), conducted an exploratory project for the NDIA regarding the reforms package in 2020 but the assessment toolkit to be used under the new model was explicitly out of scope. The association is calling for further information to be made available about the approach and for “robust evaluation measures” to be introduced. Specifically, AHPA is seeking clarity on:

- “Whether the independent assessment toolkit is appropriate for all participants and types of disability
- When other allied health assessments may be required to supplement the independent assessment process, including for issues such as swallowing safety and access to assistive technology
- Understanding how independent assessments inform plan budgets
- How the independent assessment process may affect the allied health workforce
- How the rollout of the independent assessment process is being overseen and how both the process, and the work of the independent assessor organisations are evaluated.”¹³

CYDA shares concerns about these gaps and supports the call for further evidence to be provided around the proposed approach.

Serious concerns about the current independent assessment pilot

In acknowledging how much there is to learn about assessing functional capacity and the risks of independent assessment, the community is rightfully concerned with the NDIA's efforts to gather evidence and evaluate the proposed changes. So far, the NDIA has been unable to pilot the new approach with enough participants to make accurate conclusions or to comprehensively identify any

¹¹ For example, this approach has been taken by several education departments to guide the provision of support to students with disability.

¹² Dickinson, H. (2021, March 12). 'Dehumanising' and 'a nightmare': why disability groups want NDIS independent assessments scrapped. *The Conversation*. [Dehumanising' and 'a nightmare': why disability groups want NDIS independent assessments scrapped \(theconversation.com\)](https://theconversation.com/dehumanising-and-a-nightmare-why-disability-groups-want-ndis-independent-assessments-scrapped-156941)

Add reference - <https://theconversation.com/dehumanising-and-a-nightmare-why-disability-groups-want-ndis-independent-assessments-scrapped-156941>

¹³ Australian Health Professions Australia (2020). *NDIS independent assessments and the allied health sector*, 5 October, web page, <https://ahpa.com.au/news-events/ndis-independent-assessments-and-the-allied-health-sector/>.

unintended consequences and risks. While the second pilot is still underway, the information provided by the NDIA and the consultation questions they have posed to the community are framed as if independent assessments are a given – raising questions as to whether findings from the pilot will even be properly considered. Additionally, evaluation of this pilot will be done internally within the Agency, without independent review.

This is a deep concern for CYDA as issues with the independent assessments approach being used in the second pilot have been identified by several participants, including through social media. CYDA made contact with a family member of a child with disability who had recently undergone an independent assessment as part of the pilot process and was keen to share their experiences (see the following case study).

CASE STUDY: Grace's pilot Independent Assessment

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 "destabilizing". 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. "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 a replacement for 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 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."

Failure to address existing equity issues and barriers

One of the key reasons for the reform expressed publicly by the Agency and the Minister is to address equity issues that currently exist in the NDIS. CYDA agrees that there are significant barriers to accessing the NDIS for many people, and there are barriers for many participants in accessing the supports they need and using their NDIS plans most effectively. However, we see little evidence that the proposed reforms are considering the underpinning issues creating these barriers, and we are deeply concerned that the moves may end up exacerbating current inequities and increasing the marginalisation of some communities.

Current equity issues in the access process

The proposed reforms to the access process start with the presumption that all groups and communities have equal knowledge about the NDIS and equal confidence in engaging with it. By not considering the increased barriers faced by some groups to learn about the NDIS and initiate the access process, the proposed changes fail to address current inequalities.

Recent research has explored the experiences of socially and economically marginalised individuals in interacting with the NDIS.¹⁴ The research found that many in the study sample had not even heard of the NDIS, and if they had, had no idea about how to apply for it or whether they would be eligible. The study found that when disability is overlaid with the marginalisation that comes from socio-economic disadvantage, the capacity for people with disability to participate in a complex program like the NDIS becomes problematic; and it concluded that improved communication with potential participants is needed, particularly for people from socio-economically disadvantaged and socially isolated groups.

The Tune Review also highlighted that some cohorts, namely Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, and people with psychosocial disability also face increased barriers in engaging with the NDIS.¹⁵ While acknowledging that some work was underway, the review concluded that more concerted efforts are needed to engage with people with disability who may be eligible for the NDIS but have not yet connected with the service.

To truly attend to equity issues in the access process, more focused outreach efforts are needed to engage with people who would otherwise not connect with the NDIS. These strategies should be co-designed with the communities and groups of people that are being targeted. The outcomes of these strategies should also be monitored and evaluated to understand what works and what doesn't.

Current equity issues in plan implementation

In our recent NDIS surveys we asked our community if they experienced any barriers in using their NDIS plan. Most respondents in the family and caregivers survey indicated that they had experienced one or more barriers, with only 13 per cent of respondents saying they had not experienced barriers. Two thirds of respondents reported that finding suitable services and supports in their area was a barrier to using their/their child or young person's NDIS plan (see Table 1 below). Additionally, almost half of respondents reported experiencing the following barriers:

- Finding appropriate workers

¹⁴ Cortese, C., Truscott, F., a Nikidehaghani, M., & Chapple, S. (2020) Hard-to-reach: the NDIS, disability, and socio-economic disadvantage, *Disability & Society*, AHEAD-OF-PRINT, 1-21. <https://doi.org/10.1080/09687599.2020.1782173>

¹⁵ Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*.

- Finding supports that are appropriate for children/young people
- Finding out the services and supports that are available, and how they can be accessed.

Table 1. Respondents' reported barriers to using their/their child or young person's NDIS plan (n=183)

Barriers	Number of respondents	Percentage of respondents
Finding suitable services and supports in my area	122	67%
Finding workers that are understanding and empowering	90	49%
Getting supports appropriate for children and young people	83	45%
Finding out what services and supports are available and how to access them	83	45%
Feeling safe and comfortable accessing the available supports	56	31%
Accessibility barriers	32	17%
Accessing supports that are culturally appropriate	8	4%
Other	35	19%
I don't experience barriers to using my NDIS plan	24	13%

The barriers experienced by NDIS participants in using their NDIS plan are also reflected in plan utilisation¹⁶ data.¹⁷ Average plan utilisation rates before the COVID-19 pandemic, over the period 1 October 2019 to 31 March 2020, were only 60 per cent for participants aged 0 to 6 years, and 68 per cent for participants aged 7 to 14 years.

Additionally, these data show clear inequities between groups from different socio-economic backgrounds. For NDIS participants aged 0 to 6 years, there is 12 percentage points difference in average plan utilisation between the lowest decile (indicating the areas with the highest socio-economic disadvantage) and the highest decile (54 per cent compared to 66 per cent). For participants aged 7 to 14, the difference was 7 percentage points between the lowest and highest deciles (65 per cent compared to 72 per cent).

This indicates that the current marketised service system is not meeting all support needs for children and young people with disability, and that more work is needed to provide appropriate and timely support and information for all children and families/caregivers to engage fully with the complex service system.

While the proposed introduction of independent assessments is arguably intended to address equity issues in the size of plan budgets, the reform lacks any inclusion of a strategy to address plan

¹⁶ Plan utilisation is the percentage of a participant's allocated plan that is spent or used.

¹⁷ NDIA. (2020). *Young people in the NDIS*. Available at <https://data.ndis.gov.au/media/2485/download>

implementation issues and inequities. For the NDIS to truly be more effective and fairer, targeting inequities in the service system and inequities in navigating the service system must be a priority.

Equity risks through independent assessments

Independent assessments are not, and cannot be, the silver bullet that will resolve existing inequity issues in access and planning. While the changes are hailed as making the NDIS “simpler, faster, fairer and more flexible”, the requirements of individuals to seek out and pay for diagnostic reports and other evidence (that is written appropriately) remains unchanged. If anything, the introduction of the independent assessments is just an additional step that people with disability now must take.

The proposed independent assessment process predominately requires individuals to self-report during the assessment and includes input from other stakeholders/informants in individuals’ lives. This means people who have access to greater personal resources, such as a formal education, strong English and literacy skills, and strong social networks to inform and support them before and throughout the process, are more likely to understand the process and advocate for themselves appropriately – and there is a risk that these people therefore receive better outcomes through the process as their needs will be more appropriately reflected.¹⁸ This is equally relevant to children and young people with disability, where the parent/caregiver/family’s access to resources and familiarity with the service system is likely to be an advantage.

We have serious concerns that the proposed approach is a ‘blunt instrument’ that will fail to adequately capture differences and complexities in individuals’ lives and will further marginalise people already experiencing significant inequities.¹⁹

Additionally, it is not clear how the process will work for children and young people who are not living in family environments, for example, those in the out-of-home care system, where children with disability are over-represented, or for those living in environments with adults who do not have the capacity or desire to place the child’s best interests at the forefront or to be strong advocates for the child. The proposed approach appears to rely on the assumption there is a benign and supportive adult or key informant in the lives of each NDIS participant/applicant – while this may largely be the case, we know unfortunately there are many children living in unsafe environments and many adults in coercive or otherwise abusive relationships, for whom this is not the reality. Further information is required from the NDIA as to how the process will adequately respond to the needs of individuals living in these environments or without access to a strong social network.

¹⁸ Carey, G., Malbon, E., Reeders, D., Kavanagh, A. & Llewellyn, G. (2017). Redressing or entrenching social and health inequities through policy implementation? Examining personalised budgets through the Australian National Disability Insurance Scheme, *International Journal for Equity in Health*, 16(192).

¹⁹ Fawcett, B., & Plath, D. (2014). A National Disability Insurance Scheme: What social work has to offer, *The British Journal of Social Work*, 44(3), 747–762.

Undermining of individuals' lived experience, goals, and aspirations

CYDA consistently hears the key message from young people with disability and from families/caregivers of children with disability that genuinely listening to individuals and their interests, goals and needs is vital for the inclusion of people with disability in society. This concept is built into the United Nations Convention on the Rights of Persons with Disabilities, and into the disability rights movement, with its famous: *Nothing about us, without us*. One of our participants at the 2020 National Youth Disability Summit captured this principle clearly when they said:

"Let us tell you what we need, not [you] tell us what you think we need."

Personalised supports and increasing people with disability's choice and control is also the crux of the NDIS. As part of this, and as outlined in the *National Disability Insurance Scheme Act 2013*, supports are provided to assist people pursue their goals and aspirations.²⁰ However, the proposed changes to how supports are allocated through the NDIS – namely, using the results from a functional assessment to determine an individual's plan budget – undermine these crucial principles and depersonalise the Scheme, by limiting the influence of people's goals and aspirations and restricting their ability to have a say on the supports they receive, beyond choosing providers.

"If we can't set goals then it will be hard to determine funding. However, if [independent assessments] come in funding will be determined by assessments only. Goals will become irrelevant. Choice and control will become redundant. It's a move backwards back to the medical model of disability. It makes me feel concerned and sad." - Family member/caregiver of a young person

Undermining people's agency and creating robo-budgets

In the current planning process, goals act as an important mechanism for individuals to exert their lived expertise and help determine that their plan reflects their needs and budget.

In CYDA's NDIS surveys, we asked individuals how important goal setting is in NDIS plans to get the support the respondent, or their child, needs. In the family and caregivers survey, approximately 95 per cent of respondents indicated they find the process very or somewhat important (very important: 61 per cent; somewhat important: 34 per cent). This is shown in Figure 4 below.

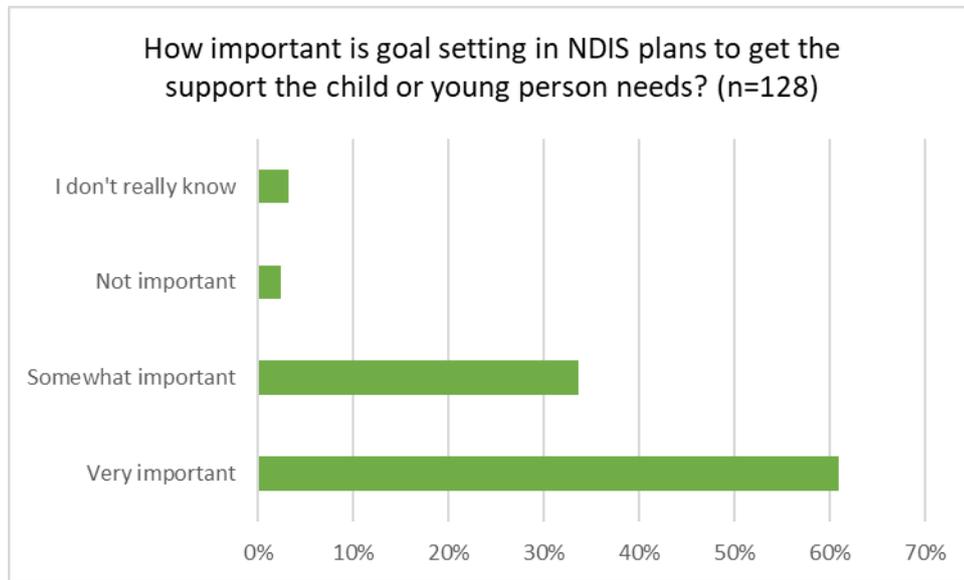
²⁰ *National Disability Insurance Scheme Act 2013* (s.34) "For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations."

Figure 4. Respondents' views on the importance of goal-setting for securing appropriate supports

Survey question: How important is goal setting in NDIS plans to get the support the child or young person needs?

(n=128)



The proposed reform indicates the inclusion of goals in the planning process will now take on an entirely different purpose, guiding how a budget is spent, as opposed to shaping a budget. While the existing process was imperfect and criticised for its opaqueness and for often failing to correctly include people's goals²¹ – the formal goal-setting process at least allowed one avenue for participants to advocate for themselves. This change ultimately means that people will now be powerless in determining what supports are included in their plan budget.

While in the proposed planning process participants will be able to view draft versions of their plan budgets, something that people with disability and the disability sector have long advocated for, there is very limited scope for participants to be able to change what is in the draft plan. To provide someone a draft, yet no authority to change it or rectify mistakes, is just as disempowering as this step not being included at all.

“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 one 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?” - Young person aged 18-25 years

Using [the] NDIS is a minefield. Our whole lives around what one planner thinks is right for us. Never had to fight so hard for something that could be so easy. We are not here to rip of the system, [we] just want what is needed.” - Family member/caregiver of a young person

²¹ Joint Standing Committee on the National Disability Insurance Scheme. (2019). *NDIS Planning Interim Report*. Available at [NDIS Planning Interim Report \(aph.gov.au\)](https://aph.gov.au/ndis-planning-interim-report)

“People don't ask for equipment because they feel like it. They ask because they need it.” - Family member/caregiver of a young person

We are deeply concerned with the introduction of a Personalised Budgeting Tool which will use the information from the independent assessments to create budgets. However, there has been no information about this made public from NDIA. Presumably, this will be a tool that has algorithms based on scores from the assessment. If so, this is a deeply flawed approach to creating a person's budget, and decoupling participants' goals from the budgeting process completely undermines the vision and goals of the NDIS. This is particularly true for young people as they are transitioning from childhood, through adolescence and into adulthood.

Safeguards and review mechanisms are limited

The Tune Review, completed in 2019, discusses the use of functional assessments but clearly states a number of key protections will be necessary; notably, *“participants having the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment.”*²²

CYDA and others across the disability community note that the NDIA has selectively used parts of the Tune Review as justification for the proposed independent assessments program, without including the necessary and recommended safeguards. For example, both the Access and Planning consultation papers²³ that the NDIA released for community feedback explicitly indicate that individuals will have very limited powers to request a second assessment or appeal the results of the assessment or the delegate's decision to not grant an exemption.

Not considering the suite of recommendations from the Tune Review and the Productivity Commission's work on the NDIS, which is also selectively used as justification for the changes, and not providing fair mechanisms to challenge independent assessments or to seek redress for complaints, means that power imbalances between the NDIS/NDIA system and individuals within it will be entrenched and likely exacerbated.

The proposed planning process also fails to mention how, or if, Plan Alignment Meetings will be included. Plan Alignment Meetings, done well, are an important safeguard in which the Local Area Coordinator (someone who has actually met the individual) has a meeting with the NDIA delegate to provide the delegate with greater insight into the participant's support needs, goals and aspirations and to work through clarifications. While this not always a perfect process, it can help to uphold the preferences and goals of the individual in the planning process.

Recent research analysed the reviews and decision of the reviews and decisions regarding reasonable and necessary funded supports of the Administrative Appeals Tribunal (AAT).²⁴ Of the 36 cases that were analysed (of which 42 per cent pertained to participants aged 26 years or younger), 47 per cent were overturned, 11 per cent were partly overturned, and 6 per cent were settled outside of the AAT or court system. Just over a third of the initial decisions were upheld.

²² Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*. p. 66.

²³ NDIS. (2020). *Consultation paper: Access and Eligibility Policy with independent assessments*. Available at <https://www.ndis.gov.au/media/2874/download>; NDIS. (2020). *Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility*. Available at <https://www.ndis.gov.au/media/2875/download>

²⁴ Venning, A., Hummell, E., Foster, M., Burns, K., & Harris Rimmer, S. (2020). Adjudicating reasonable and necessary funded supports in the National Disability Insurance Scheme: A critical review of the values and priorities indicated in the decisions of the Administrative Appeals Tribunal. *Australian Journal of Public Administration*, 1- 17.

<https://doi.org/10.1111/1467-8500.12438>

The research highlighted that there are clear discrepancies in values and in the prioritisation of reasonable and necessary support across decision-making in the NDIS administration, and it concluded that NDIS participants still do not have the level of agency in decision-making the Convention on the Rights of Persons with Disabilities would demand. This is deeply concerning when considering participants will not have the power to appeal the results of their independent assessment – the new mechanism which will determine what reasonable and necessary supports they receive – through AAT hearings, and that there is currently little information about how complaints and concerns could be raised under this approach.

While CYDA acknowledges there are some challenges in the current planning process, but by removing the few existing mechanisms and safeguards where participants can advocate for themselves, we are concerned the proposed changes will be the last nail in the coffin for the rights of people with disability being recognised and centred in the planning process. Again, we note the lack of evidence, discussed earlier in this submission, for the introduction of an independent assessment approach for planning purposes, and the safeguarding mechanisms and qualifiers mentioned by Tune and the Productivity Commission in their relevant work.

This includes:

- “The need for consultation with people with disability in implementing this approach”
- “The risk of disengagement by people with disability if there are concerns around the independence of assessors and their appointment by the NDIA, and if assessments are perceived to be “a tool designed to cut supports from participants.”²⁵

CYDA urges the NDIA not to proceed with the proposed changes to how plans are formed and instead recommends that the planning process should be reviewed and adapted with the genuine input of people with disability, their disability representative organisations and legal advocacy organisations. This is the only way to ensure the NDIS planning process upholds the authority, lived expertise and rights of people with disability, and maintains the true principle of the NDIS – greater choice and control.

Young people, family members and caregivers also shared their concerns with us in our NDIS survey:

“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.”

“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.”

“Children/young people are not likely to open up to therapists they're not familiar with, which could result in both over or under reporting of impact of disability.”

“An absolute stranger to determine my son's fate and future makes me so nervous.”

“I am so worried that he will lose his package of support if the assessors do not understand his needs.”

²⁵ Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*. p. 66.

Lack of consideration for the broader NDIS ecosystem

Workforce challenges

In their community consultation paper²⁶, the NDIA state that independent assessments will be done by “trained experts, for example occupational therapists, physiotherapists, psychologists and other health and allied health professionals”. There is already pressure on this workforce and children and young people face significant delays for diagnosis and ongoing therapies and supports. Long wait lists and shortages of specialised staff for diagnosis and ongoing support are commonly identified concerns by families of children and young people with disability.

Multiple respondents to CYDA’s 2021 NDIS Survey discussed waiting ‘months’ for services and sitting on waiting lists for occupational therapists, speech therapists and other support services.

“Some are hard to get and I am restricted by funding requirements. It’s impossible to get psychology and behaviour support in a timely manner. My child was on a waiting list for 6 months. So that was 6 months without support and you can’t spend it if you can’t get support. When we finally got behaviour support, it was terrible.”

“It took five months, from identifying significant delays to starting therapy, for my ten-month-old son, i.e., from 10 to 15 months. The process for my six-month-old son took 13 months, i.e., 6.5yrs to 7.5yrs, because he was too old for early intervention. These are significantly long times, given the crucial developmental periods involved.”

CYDA has long advocated for the NDIA to address the issues of thin markets²⁷ and to invest in workforce development. It is critical that the NDIA works with allied health organisations to build a sustainable workforce to take on this additional step if independent assessments are to be introduced. This must include co-designing the access strategy and process with allied health peak bodies to ensure independent assessments do not increase thin market issues – and if necessary, roll-outs must be delayed to allow time to build workforce to adequately deliver this additional service.

Lack of clarity around the role of support coordinators and LACs

The suite of information and consultation papers released by the NDIA do not address the future of, or any potential changes to, some aspects of the NDIS ecosystem considering the significant changes proposed to access and planning.

CYDA has previously received evidence from our members that wrap-around supports within the NDIS ecosystem, including support coordination and Local Area Coordination (LACs), are critical for a successful journey with the NDIS, particularly those accessing the NDIS for the first time. In CYDA’s previous submission to the NDIS Participant Service Guarantee and Legislative Review, we recommended that support coordination be provided for all children and young people during the implementation of their NDIS plan.²⁸ Support coordination is also crucial for participants facing additional complexity and/or barriers to accessing services, as discussed earlier in this submission.

²⁶ NDIS. (2020). *Consultation paper: Access and Eligibility Policy with independent assessments*. Available at <https://www.ndis.gov.au/media/2874/download>

²⁷ CYDA, (2019). *NDIS Thin Markets*. Available at: [NDIS Thin Markets \(cyda.org.au\)](https://www.ndis.gov.au/media/2874/download)

²⁸ CYDA (2019) *Improving the NDIS for children and young people with disability and their families: NDIS participant service guarantee and removing legislative red tape review*. Available: <https://www.cyda.org.au/resources/details/66/improving-the-ndis-for-children-and-young-people-with-disability-and-their-families>

When asked about their NDIS experience, one respondent said:

“Have had few positive experiences with my children. Finally have a few good therapists, but very worried about them being taken away. But we do have a brilliant support coordinator - have been very lucky to find her. If it wasn't for her, [the] NDIS would have been a complete nightmare.” - Family member/caregiver of a young person

It is critical that the roles of these wrap-around supports are well understood within the new system so children, young people and families can receive the supports they need under the NDIS. There is currently very little information available about these elements, which is causing added confusion and concern for current and prospective participants, and no doubt for the individuals and organisations delivering these important services.

Consider the appropriateness of independent assessments for young children

While this submission largely responds to the proposed introduction for mandatory independent assessments for current and potential NDIS participants ages 7 and up, the NDIA is also considering the introduction of a form of independent assessments for children under the age of 7 (except children under one years old).²⁹ It is proposed that Early Childhood (EC) partners would administer the independent assessments for young children rather than use a separate assessor workforce.

Although it is welcomed that the NDIA are considering a ‘tailored approach’ for children, many questions and concerns for our community remain. For instance, how will individual recent reports and assessments be included, if at all, for children? Also, what rights will children and their families and caregivers have to appeal the results of independent assessments and under what circumstances will children be exempt?

While it is not fully explored how assessment of functional capacity of a child can translate to allocation of funding, there is a strong body of work that details what best practice for assessing children entails. The Division for Early Childhood, an international membership organisation that promotes policies and advances evidence-based practices, has developed a resource highlighting the practices that have been shown to result in better outcomes for young children with disability, their families, and the people who work with them – including in assessment.

The following are recommended best-practices to guide practitioners:

1. “Practitioners work with the family to identify family preferences for assessment processes.
2. Practitioners work as a team with the family and other professionals to gather assessment information.
3. Practitioners use assessment materials and strategies that are appropriate for the child’s age and level of development and accommodate the child’s sensory, physical, communication, cultural, linguistic, social, and emotional characteristics.
4. Practitioners conduct assessments that include all areas of development and behaviour to learn about the child’s strengths, needs, preferences, and interests.
5. Practitioners conduct assessments in the child’s dominant language and in additional languages if the child is learning more than one language.
6. Practitioners use a variety of methods, including observation and interviews, to gather assessment information from multiple sources, including the child’s family and other significant individuals in the child’s life.
7. Practitioners obtain information about the child’s skills in daily activities, routines, and environments such as home, centre, and community.
8. Practitioners use clinical reasoning in addition to assessment results to identify the child’s current levels of functioning and to determine the child’s eligibility and plan for instruction.
9. Practitioners implement systematic ongoing assessment to identify learning targets, plan activities, and monitor the child’s progress to revise instruction as needed.

²⁹ NDIS. (2020). *Supporting young children and their families early, to reach their full potential*. Available at <https://www.ndis.gov.au/media/2877/download>.

10. Practitioners use assessment tools with sufficient sensitivity to detect child progress, especially for the child with significant support needs.
11. Practitioners report assessment results so that they are understandable and useful to families.”

Division for Early Childhood (2014)³⁰

As outlined above, accurate assessment is complex – with the use of assessment tools only being a small component. Further information is required to clarify whether those in the current EC workforce are qualified to do the independent assessments, or if one professional is able to do an accurate assessment alone. Then the question is – if the EC workforce is to grow so there are enough trained professionals hired by the NDIA to be able do assessments (and deliver Short Term Early Interventions and other supports), what impact will this have on the already thin market of allied health professionals that have the skillset to work with children and young people?

Literature also emphasises the importance of ‘authentic assessment’ of children – whereby assessment is most accurate when children’s natural behaviours are observed in their natural settings, such as their home or kindergarten.³¹ What is essential in this type of assessment is that the child feels comfortable and is acting naturally, as they would any other day. While the proposal of EC partners undertaking the assessment is a preferred method than a person entirely not known to the child being the assessor³², CYDA questions if all EC partners will have established a rapport enough with each child that the child will feel comfortable in their presence to behave naturally.

Acknowledging the complexities of assessment and ensuring there is a qualified workforce to run a national assessment program to a consistent level, CYDA recommends that a rigorous research and evaluation process is conducted before any decisions or changes are made to Early Childhood Early Intervention service and access eligibility. As part of this research and evaluation, parents, caregivers and disability representative organisations and early-childhood researchers and experts must be meaningfully genuinely included. So that the community have every chance to be consulted and included in an informed manner, the NDIA must first proactively engage with the community to provide information in accessible and diverse ways.

In developing an assessment framework for all children, with all needs and strengths, across all of Australia – one approach will never work for all individuals. To ensure that assessments are equitable and appropriate, the NDIA must consider alternative options to assessment, such allowing a person’s existing health professionals to complete assessments using the same tools. These alternative options should then be guided by the child’s needs and family preferences.

³⁰ Division for Early Childhood (2014). *DEC recommended practices in early intervention/early childhood special education*. Los Angeles, California: Division for Early Childhood, Council for Exceptional Children, p.14.

³¹ Neisworth, J.T. and Bagnato, S.J. (2004). The mismeasure of young children: the authentic assessment alternative. *Infants & Young Children*, 17(3), 198-211; Bagnato, S. J. (2005). The authentic alternative for assessment in early intervention: An emerging evidence-based practice. *Journal of Early Intervention*, 28(1), 17-22.

³² As proposed for individuals aged 7 and older in *Access and eligibility policy with independent assessments consultation paper*

Appendix A. Demographic data for 2021 survey respondents

Table A1 below outlines key demographic data from the NDIS experiences surveys recently conducted by CYDA.

Table A1. Demographic characteristics of children and young people (n=206)

Demographic characteristic	Number	Percentage
Gender		
Male	132	64.08%
Female	65	31.55%
Non-binary	4	1.94%
Prefer not to say	3	1.46%
Other	2	0.97%
Indigenous status		
Not Indigenous	194	94.17%
Aboriginal	8	3.88%
Prefer not to say	4	1.94%
Torres Strait Islander	0	0.00%
Aboriginal and Torres Strait Islander	0	0.00%
State / territory		
VIC	75	36.41%
QLD	58	28.16%
NSW	34	16.50%
SA	22	10.68%
WA	8	3.88%
ACT	6	2.91%
TAS	2	0.97%

Demographic characteristic	Number	Percentage
NT	1	0.49%
Location		
Metropolitan area	133	64.56%
Regional area	56	27.18%
Rural	15	7.28%
Remote	2	0.97%
Age of child or young person		
0-3 years	9	4.37%
4-6 years	13	6.31%
7-9 years	33	16.02%
10-12 years	36	17.48%
13-15 years	43	20.87%
16-18 years	17	8.25%
18-25 years	37	17.96%
25+	18	8.74%
NDIS status		
Funded NDIS participant	187	90.78%
Accessing NDIS-funded early childhood intervention supports	14	6.80%
Not sure if eligible	3	1.46%
Applied for the NDIS but deemed ineligible	3	1.46%
Eligible for NDIS but still waiting for a plan to be approved	1	0.49%
Other	1	0.49%
Length of time accessing the NDIS		

Demographic characteristic	Number	Percentage
Less than 12 months	25	12.50%
1 to 2 years	65	32.50%
More than 2 to 3 years	55	27.50%
More than 3 to 4 years	33	16.50%
More than 4 years	22	11.00%

Appendix B: Comments from family members, caregivers and young people on independent assessments

In CYDA's NDIS surveys, many family members, caregivers and young people shared their thoughts and concerns on the proposed introduction on independent assessments.

"Independent assessments make the personal care and reports my child gets from his therapists worth nothing to the NDIS, and risk that his funding won't be tailored to him. This either means we (his parents) have more work to do to advocate for him, or that there's no point in advocating to the NDIS at all. The NDIS was meant to be individualised solutions for disabled Australians. Independent assessments take away that individuality."

"The independent assessors are not experts in my child's disability, her therapist and I are and they should lead her NDIS funding not a pen pusher or the wrong allied health professional."

"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."

"An [independent assessor] cannot understand the functioning capacity of our participant in one meeting, it takes months of sessions with allied professionals to gain trust and insight to their capacity. We also don't want to speak negatively about shortfalls of our participant in front of our participant which we would need to do, to answer the barrage of questions that will be asked by the [independent assessment] because they don't know our participant, not to mention the anxiety levels brought on by having an [independent assessor] (stranger) in our home and the repercussions of that anxiety on our participant after the[y] leaves."

"It is stress and anxiety provoking for both the child and the parent and probably not very accurate either as this snapshot assessment will not be representative of this person's disability and the impact this has on his/her daily life at all. Ignoring reports from allied health professionals and medical professionals who have either known your child for a long time, or who are actually experts in their medical field, sounds absolutely ridiculous to me and will only set the [person with disability] up for failure."

"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."

"Individual assessments are inadequate at best. They are generic and inappropriate. They go against everything the NDIS is supposed to support and provide. Strangers with a clipboard of generic questions for 1-2 hrs questioning participants and families will give them zero insight into participants' needs."

“It will remove choice and control. I find it demeaning towards PWD to have to speak to a stranger. It’s a negative medical model of disability. I thought NDIS wanted to move away from that. It will result in reduced funding as I believe that’s the aim. How do we appeal? How do we work towards goals?”

“There is nothing independent about them. It’s a top down direction that will dilute reasonable and necessary support most likely the CEO following a government directive to reduce spending so they look better at the next election.”

“I am very worried that it is taking away independence from my daughter. The assessors have to interview some-one who knows her well, and she won't be there. And she won't get access to the report about what it has said about her. I would feel terrible as a parent discussing my daughter from a deficit based point of view - it was very distressing when she was first diagnosed, and it is no less distressing now. And if not me, then who? Her employer? Her friends? That completely changes the dynamic and power balance in their relationships. And it seems as though we are back to the medical model of disability which is paternalistic, based on 'experts' and deficits.”

“An assessor who doesn’t know my child or his situation won’t be able to make an accurate assessment of him.”

“Way too much power will be delivered to the assessor. The NDIS was meant to be about the individual, their disability, their life. People were encouraged to dream and set goals for themselves. I see a risk in the independent assessments with someone else — a stranger — defining and judging those goals and then we are back to causing immense harm to another generation of disabled people.”