

Submission to the National Disability Insurance Agency

Proposed changes to the National Disability Insurance Scheme access, eligibility and planning processes

Children and Young People with Disability Australia

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Recommendations

- 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 proposed changes to the National Disability Insurance Scheme (NDIS) as outlined in the *Access and eligibility policy with independent assessments (Access)* and *Planning policy for personalised budgets and plan flexibility (Planning)* consultation papers. CYDA has provided a separate response to the *Supporting young children and their families early, to reach their full potential* consultation paper.

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 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 in terms many of the solutions proposed in the consultation papers 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 access and planning processes. For a Scheme that has only recently achieved full transition, these dramatic reforms appear rushed and opaque, and lack a 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 young people. 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 reform are inadequate and must be immediately rectified before proceeding with any changes. The submission also outlines the risks and unintended consequences of the reform, 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.

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

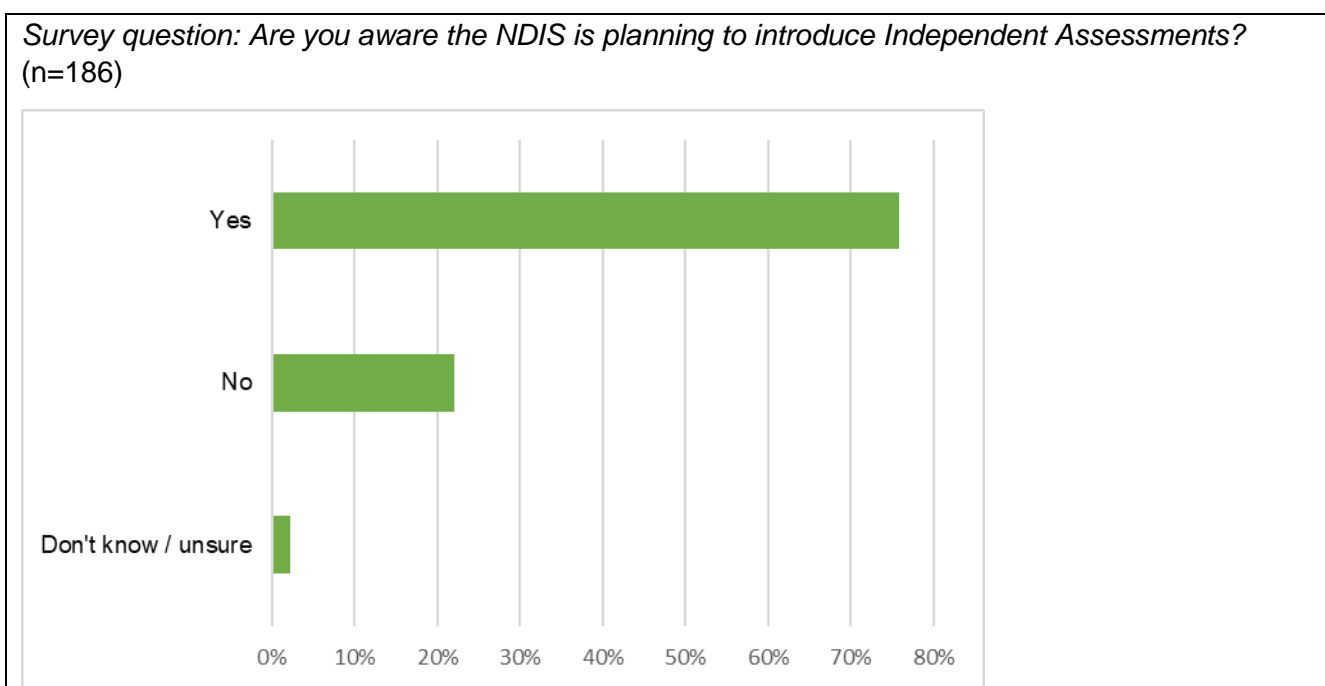
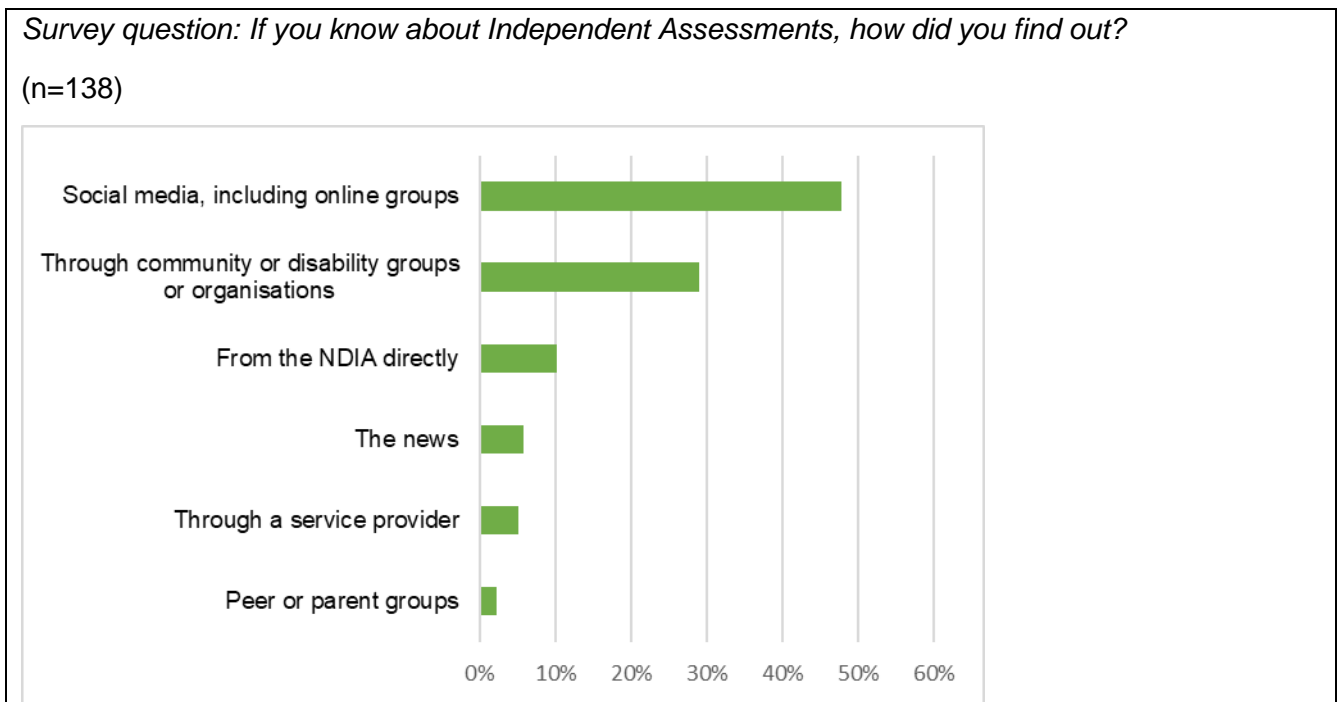


Figure 2. How respondents found out about the proposed introduction of independent assessments



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 reporting thinking the introduction of independent assessments would bring a slight or significant positive change to the NDIS, with 14 per cent undecided (Figure 3).

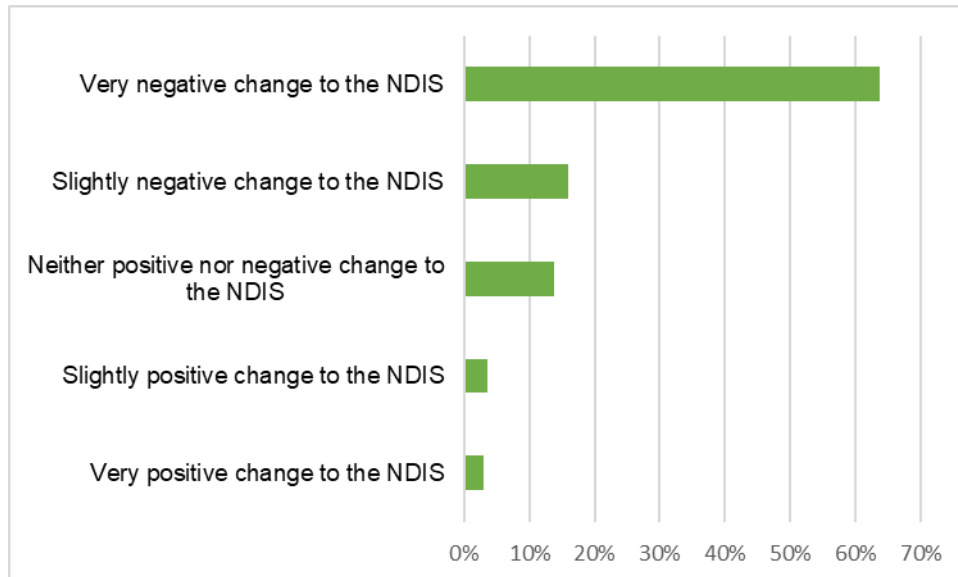
This is consistent with findings from People with Disability Australia’s 2020 survey of its members, which found around three quarters of respondents believe the rapid roll-out of independent assessments is a bad or extremely bad idea.³ Half of the PWDA survey respondents reported feeling overwhelmed by the proposals, and over 60 per cent said they feel defeated.

³ 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 or 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 or 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 are narrow and feel disingenuous, which risks exacerbating existing community distrust of the Agency. The questions in the respective

Access and Planning consultation papers fail 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.

The young people and family members and caregivers we have spoken to are also deeply concerned with the NDIA's lack of transparency and clarification around the application of independent assessments. Specifically, while we disagree that independent assessments should proceed in the current way planned, our community is calling for much clearer information to be provided and communicated widely and accessibly. This should include, at a minimum, information about the following:

- Who will be exempt from the process?
- How support packages will be calculated/
- Where support coordinators and Local Area Coordinators (LACs) will fit in/
- An estimated ratio of what will be fixed and what will be flexible funds
- When individuals have the right to seek a second assessment
- How can individuals make complaints and appeal the findings from 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).

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,⁴ 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 IA 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 IA 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.”⁵

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 IA 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 unintended consequences and risks. While the second pilot is still underway, the Access and Planning papers pose questions to the community 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.

⁴ For example, this approach has been taken by several education departments to guide the provision of support to students with disability.

⁵ 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/>.

This is a deep concern for CYDA as issues with the IA 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 rationales for the proposed reforms expressed publicly by the Agency 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.⁶ 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 a 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.⁷ 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:

⁶ 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>

⁷ Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*.

- Finding appropriate workers
- 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 utilisation⁸ data.⁹ 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 changes are arguably intended to address equity issues in the size of plan budgets, the consultation paper lacks any mention of a strategy to address plan implementation

⁸ Plan utilisation is the percentage of a participant's allocated plan that is spent or used.

⁹ NDIA. (2020). *Young people in the NDIS*. Available at <https://data.ndis.gov.au/media/2485/download>

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.¹⁰ 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.¹¹

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.

¹⁰ 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).

¹¹ 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.¹² 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 of child/young person with disability." - Family member or 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.

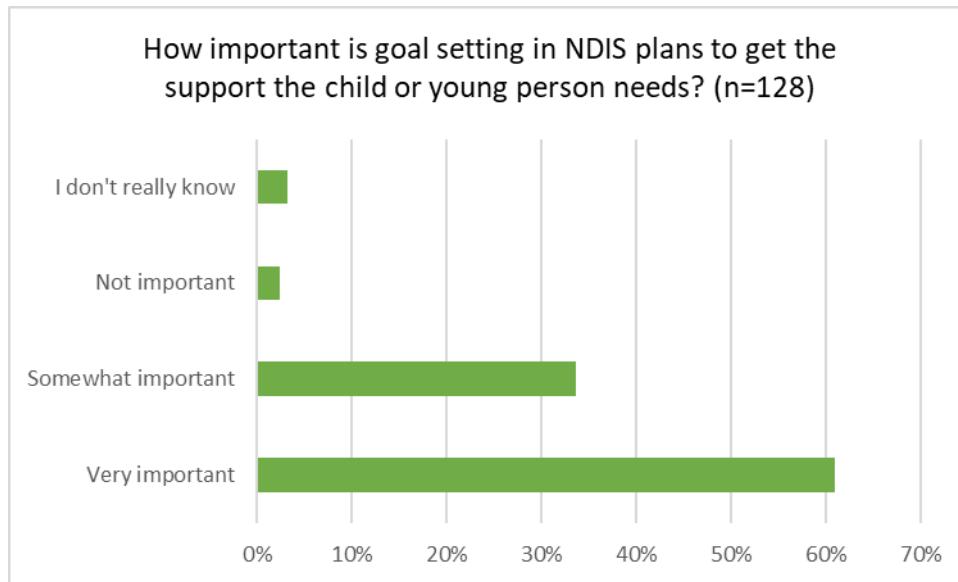
¹² *National Disability Insurance Scheme Act 2013* (s.34) "For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to 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 Planning paper 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 goals¹³ – 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 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?” - 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 or caregiver of a young person

¹³ 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 or 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 was no information about this in the consultation papers. 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 persons budget, and decoupling participants goals from the budgeting process is 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.”*¹⁴

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 papers 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).¹⁵ Of the 36 cases that were analysed (of which 42 per cent pertained to participants aged 26 years or

¹⁴ Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*. p. 66.

¹⁵ 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>

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.

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 while there are some challenges in the current planning process, 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.”¹⁶

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.”

¹⁶ Tune, D. (2019). *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*. p. 66.

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

Lack of consideration for the broader NDIS ecosystem

Workforce challenges

The Access consultation paper states 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 markets¹⁷ 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 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.¹⁸ Support coordination is also crucial for participants facing additional complexity and/or barriers to accessing services, as discussed earlier in this submission.

When asked about their NDIS experience, one respondent said:

¹⁷ CYDA, (2019). NDIS Thin Markets. Available at: [NDIS Thin Markets \(cyda.org.au\)](https://www.cyda.org.au/resources/details/66/ndis-thin-markets)

¹⁸ 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>

“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, NDIS would have been a complete Nightmare.” - Family member or 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.

Specific concerns with the proposed access reforms

Through our recent survey and the development of detailed case studies for this submission, CYDA has heard significant levels of concern about the proposed changes to the access process from young people with disability and families/caregivers.

Noting our overall concerns about the proposed reform approach outlined above, CYDA strongly considers the introduction of independent assessments as part of the NDIS access process, if it proceeds, must prioritise safety and accessibility needs of participants and provide opportunities for individuals to build trust with their assessors. People with disability experience violence and abuse at greater rates than non-disabled people, and many people with disability have histories of trauma and discrimination, as evidenced by the current Disability Royal Commission. Increased safeguarding and greater transparency around the assessment process, including the opportunity to indicate preferences as to assessor demographics, is vital to protect the safety and wellbeing of those being asked to participate in this process.

Increased administrative burden for applicants

CYDA's analysis of the proposed approach indicates that, contrary to rhetoric from the Agency, it is unlikely to reduce the administrative burden for individuals seeking access to the Scheme, and will end up adding another step and barrier to the process.

Under the new changes, making an access request and providing adequate evidence will trigger a referral for an independent assessment to take place. An independent assessment will take around three hours with some potential variation and may require an assessor to be present in the participant's home (virtually or in person).

The cost of diagnosis and acquiring supporting documents will remain significant factors. Before accessing the NDIS or the ECEI pathway, a disability or delay must be identified. The processes to identify and diagnose a disability largely exist outside the NDIS system and will be unaffected by the changes to access and eligibility. Families already report significant administrative burden and express concern over potential workload increases through additions to the process:

"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." - Family member or caregiver of young person

It's really difficult to find active, and more importantly, proactive support. I know of the local assistance but it feels very passive the process, which is really sad to experience. 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." -Young person aged 18-25

Specific concerns with the proposed planning reforms

Personalised approaches are required for pre-planning and planning

The more informed and prepared for the planning meeting a person is, the more agency they will have in planning decisions. The Planning consultation makes no reference to pre-planning or capacity building activities, or an in-depth explanation of the logistics of planning meetings. For instance, the goal setting process, which is one of the few avenues which a participant can personalise their support package, appears as if it is an afterthought. Will the goals and the participant statement be something that the individual must pre-prepare, or will the LAC actively support the individual to help identify their goals, create a timeline, and then work with the individual to explore creative ways in how they can use supports to achieve these goals?

While acknowledging that people's goals can change and it is important to be able to update them – all the responsibility of managing goals is on the individual. This raises the question, where does the LAC come in with their responsibility to support individual capacity building?

The goal setting process is incredibly important. It can act as an opportunity to, maybe for the first time ever for some, think about what their goals are, explore their options, plan for the future and be supported by someone throughout the process.

While the Planning consultation paper infers that the size of budgets will be more equitable if individual and environmental circumstances are factored in, the same logic is not applied in the proposed planning steps. Because of individual circumstances, some people do need more support. They will need more time to digest information, more encouragement to explore their goals, more guidance to support decision-making, and in some cases, active outreach to ensure they have someone in their life supporting them to achieve their goals and celebrating the wins with them.

The proposed planning steps, especially the limited and shallow focus on goal setting and the function of planning meetings beyond administration tasks, underplay what is important to people in planning, what different people need to be supported throughout planning, and what the NDIS can ultimately offer people.

Before proceeding with the changes, CYDA strongly urges the NDIA to genuinely consult (beyond the specific and limited questions asked in the consultation paper) with people with disability, their families/caregivers, and their representative organisations, about what they want and need out of the planning process and planning meetings. This includes exploring tailored options to equitably support people's different needs through planning processes.

Safeguards are needed for new planning flexibility options

The new options for longer plans and flexibility in 'check ins' will be welcomed by many in our community. However, these changes – and the onus on the individual to manage these changes – risk many individuals falling through the cracks and not being provided with the amount of support they need. For instance, regular check-ins can act as an important safeguard for children and young people who may be in settings where they are not safe or in coercive or abusive relationships.

Similarly, the structures can also help support individuals who may be struggling to manage and implement their plan and engage with mainstream and community supports. While the changes proposed are likely to increase choice and control for some, these options assume that NDIS participants are inherently 'good consumers', with the capability and agency to articulate their needs

and make decisions, access personal networks for support if necessary¹⁹, and ultimately, ask for help if needed.

The importance of regular communication and check-ins was highlighted during the first wave of the COVID-19 pandemic, where LACs, Early Childhood providers and participants and their families told CYDA how important the proactive outreach and check-ins from Partners in Community and the NDIA were in identifying who needed extra support, and then being able to provide this support. However, CYDA also received feedback that it was unclear how 'at-risk participants' were classified by the NDIA and that some participants on their caseload who they assumed would be targeted were not.

With the heavily restricted power individuals will have to appeal the results of their independent assessment (as discussed on p.17), and its subsequent impact on their plan budget and supports, the option to extend plan lengths risks producing unintended, negative outcomes for individuals. Participants may be inclined to extend the length of a plan that they do not believe meets their support needs at the risk of underdoing a new assessment which could produce an even less fit-for-purpose plan – or worse – remove them from the Scheme entirely.

If the new flexible options, such as extending plan lengths and time between check-ins, are going to be implemented, there must be a comprehensive safeguarding framework that sits alongside these processes to ensure that some participants are not disadvantaged by the one-size-fit-all, consumer-driven approach to service delivery. While some existing safeguarding policies are mentioned in the Planning consultation paper, considering the clear inequities in plan implementation (see p.12), it is clear these measures are not enough.

¹⁹ Bigby, C. (2020) Dedifferentiation and people with intellectual disabilities, Australian National Disability Insurance Scheme: Bringing research, politics and policy together, *Journal of Intellectual & Developmental Disability*, 45(4), 309-319. DOI: [10.3109/13668250.2020.1776852](https://doi.org/10.3109/13668250.2020.1776852)

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.”