NDIS Changes: What matters to Autistic young people

"NDIS can save people's lives, and it's being treated as something that just costs money."

Tahlia, focus group participant aged 15-17 years

Final Report – analysis of focus group

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cyda Children and Young People with Disability Australia

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Authorisation and acknowledgements

Authorisation:

Skye Kakoschke-Moore (she/her), Chief Executive Officer

Contact details: Children and Young People with Disability Australia (CYDA)

E. skye@cyda.org.au

P. 1800 222 660 W. www.cyda.org.au

Authors:

Dr Shae Hunter (she/her), CYDA Policy and Research Advisor

Reviewers:

Madeleine Gay (she/her), Policy and Research Advisor, Lived Experience Reviewer

Dr Tess Altman (she/her), Policy and Research Lead

A note on language: In this report, we use person-first and identity-first language. Person first language includes, “person with disability”, and identity first language includes, “disabled person.”

Thanks: CYDA acknowledges the experiences of young people with disability, and we are grateful to them for taking the time to be part of this project.



Content warning: This report references to trauma, stress, burden, and suicide.

Acknowledgements:

We would like to acknowledge the Traditional Custodians of the Lands on which this report has been developed, whose cultures and customs have nurtured and continue to nurture this Land since the Dreamtime. We pay our respects to their Elders past and present. This is, was, and always will be Aboriginal Land.

Executive summary

This report presents findings from a focus group conducted by CYDA with young people with disability across Australia in May 2026. The report centres the voices of young people who share their experiences, perspectives, and concerns about the NDIS reforms in 2026.

Ten young people with disability discussed:

- the introduction of a standardised assessment tool for determining NDIS eligibility
- cuts to social, economic, and community participation funding, and
- changes to the definition of permanence as part of determining eligibility for the Scheme.

Four key insights and solutions emerged from an in-depth analysis of these discussions, and are summarised as follows.

1. **Risk of harm**

The concept of potential for harm underpinned young people's discussions about assessment tools, funding cuts, and changes to NDIS rules. These concerns must be taken seriously. The potential harm arising from NDIS reforms is not simply a matter of reduced funding. It is a question of safety, inclusion, and fundamental human rights.

Solution:

Safeguarding must be central to NDIS reform, not an afterthought. Guarantee no-gap safeguards, with transparent, accessible, and child-friendly complaints and feedback mechanisms. No child or young person should lose access to essential supports without a safe, appropriate, and accessible alternative already in place.

2. **Lost connection**

Children and young people have a right to meaningful connection, and this should not be reduced by NDIS reforms. Recognising that funding cuts will impact their capacity to form and maintain these connections, young people fear for their mental health and wellbeing. Young people with disability already experience a much higher level of psychological distress than their same aged peers, and these cuts will worsen these outcomes.

Solution:

Provide a suite of developmentally appropriate supports that are suitable for key life stages and transitions, place-based (including online), and designed and led by peer groups.

3. **Misalignment between lived experience and government treatment of functional capacity**

Functional capacity is individual, context dependent, and sometimes fluctuating. Standardised tools with static measures cannot account for these factors, or the various adaptations young people already make to live with disability in a world not designed for them. Children and young people have the right to express their views on matters that impact them.

Solution:

Changes to access and support through NDIS and other streams should be co-designed by children and young people with disability, to ensure their needs and existing adaptations can be recognised and incorporated into service design.

4. **Hard choices**

NDIS reforms will lead to young people having to make hard decisions about the capacity, autonomy, and independence they have developed. Children and young people with disability should not be faced with impossible choices, such as choosing between using their support funding to attend university, or visiting a family member.

Solution:

Provide funding for transport and individualised support to enable children and young people with disability to genuinely and meaningfully participate in mainstream services.

Overall, the findings demonstrate that NDIS reforms represent an unacceptable level of risk of harm for children and young people with disability. The government must respond proportionately to the potential for harm by ensuring appropriate alternatives and safeguards are put in place.

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 large national networks of 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 in Australia will fully exercise their rights, realise their aspirations and thrive in all communities. We do this by:

- Raising community attitudes and expectations
- Championing initiatives that promote the best start in the early years for children with disability, their families and caregivers
- Leading social change to transform education systems to be inclusive at all points across life stages
- Advocating for systems that facilitate successful life transitions to adulthood
- Leading innovative initiatives to ensure the sustainability and impact of the organisation and the broader sector.

CYDA values the lived experience of the community as a basis for driving systemic change and advocating for system reform that meets the needs of children and young people with disability.

Background

On 22 April 2026, the Australian Government announced the Senate Inquiry into the NDIS Amendment (Securing the NDIS for Future Generations) Bill, which represented the most sweeping change to this legislation since its introduction.

CYDA responded to the introduction of this Bill with an advocacy campaign to support and represent our community of children and young people with disability and their families. As part of this campaign, CYDA facilitated a focus group with 10 young Autistic people, to identify and analyse their concerns and perspectives of the proposed changes before they were enacted into law in August 2026.

This report shares the findings from CYDA's lived experience focus group, outlining the sentiments about changes to access and eligibility, funding cuts, and new definitions of permanence.

About this report

This report provides comprehensive findings from CYDA's **focus group, "NDIS Changes: What Matters to you?", held on Wednesday 20th May 2026.** It involved 10 young Autistic people discussing the potential impacts of new functional capacity assessments as a means of accessing NDIS, cuts to social and community participation funding, and changes to rules about permanence and eligibility.

Findings are discussed in the context of the federal government's vision for Australians with disability outlined in Australia's Disability Strategy 2021-2031:

"The strategy's vision is for an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community."

Our analysis is also directed by our commitment to the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

The introduction of the National Disability Insurance Scheme in 2013 was a watershed moment for disability rights in Australia, moving from a welfare-based model to one that enacted individual rights. By prioritising the autonomy and full inclusion of people with disability, it strongly adhered to our commitment under the UNCRPD.

The 2026 reforms, proposed by the government as a means of ensuring the scheme is financially viable into the future, have been described by those in the disability community as a winding back of disability rights.

As the reforms take effect, CYDA is deeply concerned for the rights and wellbeing of children and young people with disability and their families across Australia.

How to read this report

Direct quotes from participants are indented and in inverted commas. Pseudonyms are used to protect privacy, and some quotes have been modified for brevity and/or clarity.

Thematic analysis of focus group transcripts and group chat was used to produce topic findings in Section 1 of this report and in-depth themes in Section 2. This process has led to a coherent and meaningful account of the lived experiences of NDIS participants to inform the solutions presented in Section 2.

Focus group details

CYDA's process for ethical consultation

CYDA undertakes the following as **standard best practice for ethical and inclusive consultation**, both in person and online, involving children and young people with disability:

- Consent process includes participants' permission for their de-identified data to be included in this report
- Access and support needs are determined prior to each session and feedback options on accessibility are provided afterwards
- All focus group materials (agenda, session slides, and discussion questions) are provided before the focus group
- Renumeration is provided in recognition of the value of lived expertise
- Options to participate and provide input in multiple formats are given, including by speaking, typing into the chat, emailing after the focus group or participating with a communication partner
- Risk mitigation protocols are enacted to ensure authenticity of participants for the focus group, including: checking IP address locations, verifying phone numbers, calling participants to confirm their details, and requesting cameras are turned on at the beginning of session to verify their identity.

CYDA also ensures a Safety and Wellbeing Officer with trauma informed training is available for the duration of the focus group and for one hour following, should participants require it. Facilitators introduce the person in this role and provide details at the beginning of the session, as well as several reminders throughout the session.

Participants

The online Zoom focus group was attended by 10 young people aged 15-24 years, with the following characteristics:

- All identified as Autistic and were NDIS participants
- Four were aged 15-17 years
- Six were aged 18-24 years
- Seven indicated they had ADHD
- Four indicated they had a physical disability
- Three indicated they had a psychosocial disability or mental health condition
- Two indicated they had a learning disability

- One person identified as Aboriginal or Torres Strait Islander
- Two people identified as culturally and linguistically diverse
- Four identified as LGBTIQA+
- Two were from non-metropolitan locations
- Two participants used a communication partner to assist with communication during the focus group.

The focus group was broken into two breakout rooms with four participants aged 15-17 years in one group, and six participants aged 18-24 years in the other. There was a lead facilitator and co-facilitator in each breakout room, and a Safety and Wellbeing Officer moving between the groups during the session.

Of the CYDA staff:

- One identified as a young person with lived experience of disability
- One identified as having lived experience of disability
- Two identified as having family experience of disability.

Pre-focus group activity

With the aim of understand young people's experience of completing a standardised assessment, all participants were asked to complete the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0). Participants completed a 36-item scale and recorded their feedback on this experience to share in the focus group.

Focus Group questions

The use of a standardised assessment tool to determine eligibility

Q1. What was your experience of completing the assessment tool?

- What parts felt easy or hard to answer?
- Were any questions confusing or unclear?
- Did the questions feel relevant to your life?

Q2. Do you think this tool is a good way to understand Autistic young people and their support needs?

- What did the tool understand well about you?
- What did it miss about your needs or daily life?
- Did it reflect how you function in different environments (home, school, university, community)?

Q3. Do you think this tool would lead to fair decisions about who gets NDIS support?

- Who might be left out or misunderstood by this tool?
- Are there people whose needs might not be understood in this type of assessment?

- What would you change about the tool so it captures the information needed when deciding if someone should be eligible for the NDIS?

Reduction in funding for social, economic, and community participation

Q1. How do you currently use your NDIS social, economic, and community participation funding (if you have it)?

- Do you use it for support to go out into the community (e.g., exercise, swimming, events, groups)?
- Does it help you take part in activities you would not be able to do on your own?
- How does this support help you feel included or connected to others?

Q2. If this funding is reduced, what would change for you or other Autistic young people?

- What activities or community experiences might you have to stop or reduce?
- Would it affect how easy or difficult it is to leave the house or take part in community life? In what ways?
- What impact, if any, could it have on things like independence, confidence, or feeling included?
- Do you think some groups of young people might be affected differently? If so, who and how?

Permanence and eligibility

Participants in the 15–17-year-old breakout room were asked the following additional questions, as the group was running ahead of schedule:

Q1. Before being able to apply, NDIS might make people try **appropriate treatments** and show these have not improved, reversed, or alleviated the impact of the "impairment".

- Do you think it's fair to have to do lots of treatment before being considered for NDIS?
    - Who might miss out if this happens?
- What if you were made to do a treatment that you felt uncomfortable with to prove you needed NDIS support?

Q2. If you were deemed not eligible for NDIS, what action would you take? Where would you go for support?

Section 1: Findings from focus group topics

This section describes the experiences and concerns young people shared about the proposed use of an eligibility assessment tool, changes to social and community participation funding, and changes to how permanence is defined by the NDIS.

Reflections on eligibility assessment tool

As part of the proposed changes to NDIS legislation, the government announced the use of a standardised assessment tool to determine eligibility to the Scheme.

At the time the focus group took place, the government had not provided detail about the assessment tool that would be used. To facilitate a productive discussion, CYDA provided the World Health Organisation's Disability Assessment Schedule (WHODAS) as an example of a functional capacity assessment tool, and user tested it with young Autistic NDIS participants to understand their experience.

Overwhelmingly, young people in CYDA's focus group felt that a single standardised assessment tool could not be broad enough to capture the lived experience of the user, or accurately reflect the nuance of living with disability across a variety of contexts. They concluded that a standardised assessment tool was not a fair or accurate way to determine eligibility for NDIS.

> "It's so hard to standardise something that is so individual, because at the end of the day, we all have different disability experiences and different lives that we're trying to live…I just don't think it's fair in general." - Silvia, 18-24

> "It doesn't do a good job of understanding Autistic young people." - Cosima, 18-24

Further discussion about the standardised assessment tool revealed **five key concerns:**

1. **Static metrics cannot capture the complexity of lived experience in social and environmental contexts**

There was broad agreement across both age groups that a standardised tool cannot accurately capture the complexity of how a person's lived experience of their social and environmental context impacts the level of support they might require.

> "This doesn't ask for context, it doesn't ask for a person's environment or their support systems, or, you know, who they have around, or, you know, the toll that it takes on their mental health. It just doesn't seem like a sustainable way to decide if someone is eligible for the NDIS or not." - Silvia, 18-24

> "Assessments should include real-life impacts, carer input, and individual daily support needs. NDIS decisions should look at the whole person and their long-term functional impact, not only one assessment tool." - Jamie, 15-17

One young person explained that he attends an online school, and thought the questions about school were,

> "… not specific enough… things are quite different for me now, because digital everything." - Daniel, 15-17

> "I just find it incredibly ignorant to dictate lived experience into a numbered scale of zero to four. Disability is so much more complex and layered than that." - Silvia,18-25

2. **Relies too much on the individual's understanding of themselves and their condition**

Some of the young people noted that relying solely on self-reporting might mean those with less awareness of their disability and impairment are not recognised for their support needs.

> "Lots of these tools rely on self-identification and putting yourself in those boxes…I feel like it would be good to be able to have a few more questions that have input from your peers because not everyone is able to like self-identify and realise that something they do is like quote unquote abnormal." - Tahlia, 15-17

3. **Does not account for fluctuating capacity of some conditions, especially with the use of a 30-day timeframe for thinking about functional capacity**

Most young people across the two age groups noted fluctuations in capacity as something important for any assessment to understand, and something they did not think this tool could capture.

> "Gabriel's functioning can vary quite a lot, quite significantly between different environments. So, it would be really helpful to have that put into a tool, so that people with disability can really have their voices heard around their different areas of functioning based on their environments." - Gabriel, 15-17,via communication partner

> "Some people have chronic illness and disabilities that can fluctuate, so maybe in the last 30 days someone didn't need any help, but maybe before that they needed a lot of help, and they're going to need a lot of help again." - Cosima, 18-24

4. **Does not account for the costs of maintaining functional capacity or the adaptations already made to fill gaps**

A few of the young people noted the cost borne by the young person with disability for maintaining their functional capacity across time, and how this was not something the tool appeared to recognise:

> "At one point it was asking questions about just how you cope in general, and I just feel like it's worth pointing out that you know there are ways you can cope, and then

there's healthy ways you could cope, and it kind of didn't really, as someone else mentioned earlier, it didn't reflect a bunch about functioning in different environments." - Tahlia, 15-17

"Most people with disability are incredibly high functioning, and they're able to achieve a lot of different things, but that's under so much pressure, and having to force ourselves to adapt to systems that are innately inaccessible, and it's a constant push through the discomfort of trying to confine into what society has deemed normal." - Silvia, 18-24

5. **Risk of excluding people with intellectual disabilities, invisible support needs, trauma, those who mask their needs, and minimal or non-speakers**

There was deep and genuine concern in the discussion, that those who are multiply marginalised might miss out on accessing support they genuinely need:

"WHODAS may not always be fair because hidden, fluctuating, or complex disabilities can be misunderstood. People with ASD, ADHD, trauma, or language barriers may be overlooked." - Jamie, 15-17

"I feel like it could very easily leave out people with, like, intellectual disabilities or just people in general that aren't able to self-identify." - Tahlia, 15-17

"Gabriel feels that the WHODAS tool isn't fair either. He said it could potentially miss people with invisible support needs, and also those who mask or have fluctuating capacity." - Gabriel, 15-17, via a communication partner

Young people's discussion captured the inherent bias and unfairness of using a standardised assessment tool to determine eligibility for NDIS. They noted the multiple ways a tool such as WHODAS could lead to children and young people with disability falling through the cracks, and not having their disability support needs recognised. These included lack of social and environmental context, rigidity of static measures, issues with self-reporting, fluctuating capacity, the cost of maintaining current capacity, adaptations already in place, and further marginalising already marginalised groups. These concerns mirror findings in an Ombudsman report[1] on the standardised assessment tool and process used to determine support packages.

Reflections on changes to social, economic, and community participation supports

The government announced that the funding category for social, economic, and community participation in participant budgets would be cut by 50 percent. At the time of the focus group, details about the timing and implementation for this change were not known.

[1] Commonwealth Ombudsman (2026) Automation and Oversight in Aged Care

All but one focus group participant currently use social, economic, and community funding from their NDIS plans. The young person who is not currently accessing this funding has done so in the past. Young people described how they have used their social, economic, and community support funding in the past and present, and highlighted their concerns about losing this funding.

Young people use the funding in this category for support workers to assist them with daily responsibilities, and to attend appointments, sport, and community activities.

> "I use my NDIS social and community funding to go to activities, exercise, swimming, playing tennis, and community events with support workers." - Jamie, 15-17

> "A support worker helps me with shopping and arrangements of some appointments." - Andy, 18-24

> "Teaching me life skills like cooking and operating a household." - Cosima, 18-24

They described their increased capacity for social communication, management of anxiety and sensory overwhelm, and overall independence, as a result of using this funding category.

> "It's just been major, major help for my capacity." - Daniel, 15-17

> "It helps me leave the house, meet people, and feel included, and makes me relax. Without support, I would struggle with anxiety, communication, sensory issues, and joining activities independently and confidently." - Jamie, 15-17

Young people are deeply concerned about losing access to this funding or having it reduced:

> "The impact would be very, very significant." - Nathan, 18-24, via communication partner

Their specific concerns centred on the following **five areas**:

1. **Not being able to access school, higher education, and work**

Missing out on education and employment opportunities directly infringes on the human rights of children and young people with disability to be educated and employed on the same basis as their peers without disability. Many of the young people in the focus group were concerned about their future ability to access education, or find and maintain employment. They worried about not having access to transport to attend education or work if support worker funding was cut, and needing support with finding work.

> "I'm in high school, and it's really hard for me to cope, even with support workers." - Jamie, 15-17

> “I won't be able to get transported to TAFE, which will impact my future learning capacity, and my support worker also helps me to apply for jobs, which I can't do on my own, because job ads are so inaccessible.” - Cosima, 18-24

2. **Losing the skills, independence, and autonomy they have developed**

Many young people were distressed at the thought of having to return to being more dependent on parents, caregivers, and others, and the overall loss of their autonomy.

The main concerns shared by young people about changes to this funding category were unfairness of changes and predictions of significant harm. Social isolation and the mental health implications of this were of biggest concern:

> “His independence goes down when he's not connected, feeling connected to other people.” - Nathan, 18-24, via communication partner

> “I'm dependent on that support worker for transport, cleaning, gardening, social contact, and teaching me life skills like cooking and operating a household, if so, if my community budget is cut, I will lose almost all of my independence from my parents.” - Cosima, 18-25

3. **Safety concerns**

The majority of young people raised concerns for the safety of themselves and others due to the cuts to this funding category.

> “I can't imagine not having it, because as someone with deteriorated vision, it is so difficult for me to navigate newer environments, it's unsafe for me to navigate newer environments independently, and it is also very mentally exhausting. There's so many things that I can do, and I know I can do. With the right support I'm so much higher functioning and happier.” - Silvia, 18-24

4. **Decline in mental health and wellbeing**

In discussions, young people connected their safety and wellbeing to being able to go out in their community in the same way that their peers without disability can. They told us about the potential impact to their mental health and sense of belonging in the world of losing this option.

Children and young people with disability are at increased risk of being excluded from the everyday lives of their peers without this funding. Reducing their capacity to build social connections and experience a sense of belonging in their community will significantly harm their development. This will have a compounding effect on children under 16 years, due to the impact of social media age restrictions. Restricting access to online support systems and communities that may have otherwise acted as an alternative for those unable to access physical communities for support and connection severely limits choice, control, and wellbeing.

> “It will impact my social health, social emotional health, will impact my capacity, my independence.” - Daniel, 15-17

> “If this funding is reduced, I may stop activities, social programs, and community outings. It would become harder for me to leave the house, build confidence, and stay connected with others.” - Jamie, 15-17

5. **Worry for others in the community**

Young people in the focus group showed their concern for the wellbeing outcomes of others in the disability community. Throughout the discussions, they showed awareness of their position as self-advocates, repeatedly pointing to those whose perspectives might be left out of the conversation.

> “If they want to make it so people don't have to rely as much on these social supports, they need to find other ways to support those people, like skill building and stuff It just feels like it's assuming that people are capable of completely taking care of themselves, or that they have someone there who can. Not everyone has those. Some people are just so isolated that it's not possible for them.” - Tahlia, 15-17

Overall, young people demonstrated a high level of concern and distress when discussing cuts to social and community participation funding. They were worried for themselves and others in their community. Being able to participate in social activities and events, both online and in person, was seen as a critical part of maintaining functional capacity for young people. Young people felt strongly that they would miss out on opportunities to participate in the workforce and their education if this funding category is cut. They were also deeply concerned about the harm that could occur if they were unable to attend appointments, do their shopping, or run errands on an equal basis to their peers without disability.

Reflections on changes to permanence

At the time of the focus group, the government had announced it would change the requirements for determining the permanence of disability, which would in turn impact access to the Scheme. Applicants to the Scheme would now be required to undergo standardised assessment to determine whether an impairment was permanent or could be alleviated, and to demonstrate that they had tried all appropriate, safe, and publicly funded treatment options for an impairment.

The four participants in the breakout room for 15–17-year-olds discussed changes to the rules on permanence in NDIS funding. The other breakout room did not discuss this topic due to time constraints.

The group’s unease about this change was summed up by Daniel:

> “I think this is pretty ableist and offensive policy, because if you're saying permanent… this whole thing doesn't make sense when you can get a diagnosis of something permanent, like Autism.” - Daniel, 15-17

Their specific concerns fall into the **following four areas**:

1. **Choice and agency in treatment**

Young people expressed alarm that they might be left with no choice but to try treatments they do not want to, especially medications.

> “It's important they still have a choice.” - Tahlia, 15-17

> “Not being forced to do treatments that people might not be willing to actually participate in.” - Gabriel 15-17 (via communication partner)

> “You can look everywhere and you'll find some experimental kind of, like, drugs or medicines.” - Tahlia, 15-17

2. **Cost, safety, and mental health barriers to accessing “all available treatment”**

The group identified prohibitive costs, feeling unsafe, and mental health implications as possible barriers for accessing treatments. They were particularly concerned that this approach was deeply unfair given these barriers.

> “I do not think it is fair to force people to try many treatments before getting NDIS support. Some treatments may not work for me or may feel unsafe. People with Autism, anxiety, trauma, or low income could miss out.” - Jamie, 15-17

> “Not everyone's going to be able to afford this, so if they can't afford the initial list of treatments, does that automatically disqualify them from getting that support that they greatly need from an NDIS plan.” - Gabriel, 15-7, via communication partner

> “They shouldn't be forced to do something just so they can prove that they need help, because it can also be extremely expensive…It makes it so you can't really access that sort of stuff until you've done all of these treatments, and that might be very unsafe, or just might not really apply to you.” - Tahlia, 15-17

3. **Who gets to decide what is appropriate treatment and length of time?**

Young people wanted clarity on who would be defining “appropriate treatment” and assurances that they would be included in the discussions that led to a definition.

> “Will there be a specific list of treatments based on the impairment, and if so, who is going to be saying what the treatments are? Are people with disability going to be able to weigh in on what those treatments or are people just going to be left to guess and spend a whole bunch of money and a whole lot of time trying to go

through treatments that they think the NDIS are wanting them to do.” - Gabriel, 15-17, via communication partner

“They need to explain what they mean by trying appropriate treatments, because some things will be appropriate for one person and not for another.” - Tahlia, 15-17

4. **Issues of consent**

The ability to consent to treatment was raised as a possible concern with this approach.

“If you're a child, how can you consent to something that might have insane impacts on you on in the future?” - Tahlia, 15-17

These four concerns also reflect the deepening mistrust young people have for the NDIS.

Section 2: Insights and solutions

This section of the report presents findings from a more in-depth analysis of the focus group. Transcripts from each breakout room and the chat function were thematically analysed to move beyond topic summaries about what young people said in response to the questions.

Considering the experiences and perspectives of young people at a conceptual level enables us to present four important insights that can inform more effective and sustainable policy.

Risks of harm

Underpinning discussions about assessment tools, funding cuts, and rule changes was the concept of harm. Having outlined the level of skill, enjoyment, and inclusion that NDIS access has enabled in their lives, young people shared a sense of profound concern for what daily life would be like in the future for themselves and others in the disability community.

> “People don't realise, like, they take it for granted that they can just hop in the car and, you know, or hop on a bus, so yeah, it would be a very significant, like, catastrophic impact if Nathan lost the social and community funding.” - Nathan, 18-24, via communication partner

> “It's scary thinking about how many people will just be left alone.” - Tahlia, 15-17

> “I've been in dark places where I didn't have support.” - Silvia, 18-24

Many young people began to speak about their future without support from NDIS, and did not finish their sentences or diverted to talking about their concern for others or the whole community.

> “It just doesn't feel right. That was honestly what concerned me most about this budget shift, because what am I supposed to do?” - Silvia, 18-24

> “It's quite scary, I don't want to go into it too much, but I feel the impact would be very, very significant, as in I feel it would impact his safety.” Nathan, 18-24, via communication partner

They cited the lack of fairness in the reforms, noting the various groups who could be overlooked throughout the reform processes, and be harmed by missing out on critical support. A high level of lateral care and empowerment was woven throughout discussions in both breakout rooms, with young people demonstrating their care and concern for others by highlighting their humanity.[2]

[2] Clark et al. (2024) Learning From Community Voices About Lateral Violence and Lateral Empowerment: A Scoping Review of Grey Literature. *Australian Journal of Psychology, 76*(1), 2353055.

> "It's real people who will be confined…people could actually get seriously impacted, like hurt, from having these really important things just taken away from them. It's a much bigger thing than just cutting some money." - Tahlia, 15-17

Young people can viscerally imagine this harm, because many of them have already experienced it. The sweeping reforms generated by the NDIS Amendment (Securing the NDIS for Future Generations) Act 2026 have the potential to create significant harm to children and young people with disability. Diverting children and young people from the Scheme using standardised, automated processes with prohibitive criteria and applying blanket plan reductions risks pushing them into segregated and strained systems. The Disability Royal Commission found this to be a serious risk factor for violence, abuse, neglect, and exploitation.[3]

Solution: Effective no-gap safeguards with transparent, accessible and child-friendly complaints and feedback mechanisms

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Safeguarding must be central to NDIS reform, not an afterthought. No child or young person should lose access to essential supports without a safe, appropriate and accessible alternative already in place.

While improving Scheme integrity, sustainability, and participant safety are key objectives of the reforms, these goals cannot be achieved by shifting risks and responsibilities onto children and young people. The government should invest across existing NDIS supports and new services, including foundational supports, to ensure reforms do not inadvertently increase exposure to harm.

Safeguards must go beyond worker screening, codes of conduct and mandatory training, and respond to the risks that children and young people with disability identify in their everyday lives. This includes loss of support, social isolation, exclusion, and unsafe transitions between services.

Children and young people with disability must be meaningfully involved in designing, monitoring and evaluating safeguards that ensure continuity of support, supported referral pathways, flexible entry points, equitable access, and child-friendly accessible complaints mechanisms.

A rights-based approach must underpin every stage of reform, recognising children and young people with disability as rights holders, not simply recipients of services. Consistent with the UNCRPD and the United Nations Convention on the

[3] Disability Royal Commission (2023) Final Report - Volume 3, Nature and extent of violence, abuse, neglect and exploitation

Rights of the Child (UNCRC), this requires governments to prioritise safety, dignity, inclusion, choice and control, and the best interests of the child.

The measure of successful NDIS reform cannot be savings alone. It must be whether children and young people with disability are safer, better supported, and able to participate fully in their communities.

Loss of connection and fears for mental health

The need for connection with others is recognised by neuroscientists and epidemiologists as a biological imperative equivalent to our other basic needs such as food and shelter.[4] Just as we experience harm when we do not have food, social isolation is also detrimental to our health and wellbeing. When children and young people with disability are excluded from systems, activities, and relationships, their bodies and brains experience a stress response similar to that of hunger or thirst. They are being prevented from accessing a fundamental need and this will have serious adverse effects on their wellbeing.

Both formal and informal interactions in their local and online community during practical tasks and recreational activities help young people build confidence in themselves and feel safe and connected.

> "Meeting like-minded people that all had similar interests just made me feel like a lot more comfortable when learning and doing new things." - Tahlia, 15-17

Faced with NDIS reforms that remove opportunities for supported connections, young people shared their fear of being isolated, losing their confidence, experiencing increases in social and general anxiety, and feeling unsafe.

> "Many young people who need more support could become isolated, anxious, and less independent, especially those with higher support needs like me, and communication difficulties." - Jamie, 15-17

> "It would have a massive effect if that funding category was to be removed from people's plans. It does help him take part in activities, because it helps Gabriel to reduce his stress and to help him feel included amongst his peers in the community, so it lessens the chance of being isolated, which is massive." - Gabriel, 15-17, via communication partner

[4] Tomova et al. (2020) Acute Social Isolation Evokes Midbrain Craving Responses Similar to Hunger. *Nature neuroscience*, *23*(12), 1597–1605; Holt-Lunstad (2022) Social Connection as a Public Health Issue: The Evidence and a Systemic Framework for Prioritizing the "Social" in Social Determinants of Health. *Annual Review of Public Health*, *43*, 193–213

It is widely acknowledged by neuroscientists that the brain of typically developing humans is still undergoing maturity into their twenties.[5] Newer research demonstrates that the brain reaches maximum efficiency and integration at 30 years old.[6]

Young people with disability aged 18-24 report the highest level of psychological distress out of all age groups of people with disability, with 55.2 percent indicating high or very high distress. This is also significantly higher than their same age peers without disability, with 9.6 percent reporting high or very high levels of distress.[7]

Given this, young people with disability require a more focused and resourced approach to prevent harm to their mental health and foster their psycho-social wellbeing.

Solution: Provide a range of developmentally targeted supports that are place based, peer-led, and flexibly scaffolded across Australia

In keeping with Australia's obligations as signatories to the UNCRPD, children and young people with disability have a right to full and effective participation and inclusion in society and equality of opportunity. Therefore, the opportunities for participation and inclusion that have been removed or reduced by cuts to social, economic, and community funding need to be counteracted through new supports targeted to stages of development and key life transitions.

New streams of support should be available in the local and online communities where children and young people need them. They should be co-designed with users, prioritise services that are strengths-based and peer-led, and offer the flexibility to step in and out as needed. Success should be defined by support users.

New support streams should also have a low administrative burden for children and young people with disability and their families.

[5] Snowdon (2025) No, Your Brain Doesn't Suddenly 'Fully Develop' at 25. Here's What the Neuroscience Actually Shows. The Conversation.
[6] Mousley et al. (2025) Topological Turning Points Across the Human Lifespan. *Nature Communications*, *16*(1).
[7] AIHW (2026) People with Disability in Australia - Health Status

The misalignment between lived experience and the government concept of functional capacity

Young people understand that a functional and effective support environment requires differentiation, not standardisation, in both assessment and service delivery.

On the whole, young people suggested "personalised, individualised content, context-dependent answers" (Liana, 18-24) should guide the NDIS in understanding their access and support needs.

Silvia explained that many young people with disability are already making adaptations to maintain or increase their capacity to function in communities which are not fit-for-purpose. She described the efforts and adaptations she makes when navigating new environments as a person who is legally blind as "mentally exhausting".

She reflected on the use of a standardised assessment tool to determine NDIS access, saying:

> "It doesn't really capture the planning or even the recovery that might be involved in functioning independently…or the burnout and the exhaustion with a simple yes and no kind of situation…having to force ourselves to adapt to systems that are innately inaccessible, and it's a constant push through the discomfort of trying to confine into what society has normal has deemed normal." - Silvia, 18-24

Cosima agreed, explaining,

> "Yes, someone can do something, but after what adjustments, after what equipment, after what adaptation." - Cosima, 18-24

Young people spoke about sensory overload, burnout, and masking, and the things they do to recognise and manage these:

> "Fatigue and sensory overload are not always the same in every single environment, it can fluctuate." - Gabriel, 15-17, via communication partner

The need for input from those with lived experience was considered necessary by young people in the focus group. Nathan (18-24) suggested any tool determining access to NDIS "needs an inside perspective" to reflect the reality of everyday life as a young person with disability. Tahlia pointed out a pitfall of using a tool that isn't designed by users is that,

> "…everyone's normal is completely different." - Tahlia, 15-17

The NDIS was founded on the principles of choice and control and person-centred design. It was created to address the lack of choice and flexibility in standardised block-style funding. The introduction of standardised assessment tools to determine

eligibility and blanket cuts to supports risks the very principles and rights-based approach that the NDIS was founded upon.

Solution: Co-design supports with children and young people so their needs and existing adaptations are recognised and incorporated into supports

Changes in the way access to the NDIS and other support streams are determined must be co-designed with children and young people so that their needs and the adaptations they are already making are fairly considered.

Under the United Nations Convention on the Rights of the Child, children and young people have the right to:

6. freely express their views in all matters affecting them, and adults must give those views due weight.[8]

When children and young people with disability are included in co-design approaches that build support environments for the future, this right is upheld and they are supported to build capacity to recognise and advocate for their access needs.

Hard choices, lost skills, less independence

Young people used reflective and tangible examples to demonstrate how cuts to the funding category for social, economic, and community participation, or total loss of access to the NDIS, would impact their skills and independence, leaving them to make difficult choices.

One young person imagined a future in which they didn't have access to the support workers who enable them to live a life independent of their parents.

> "If my community budget is cut, I will lose almost all my independence from my parents, because I will be depending on them for transport and all of that. I will need to accompany my parents on trips because there will be no one home to support me." - Cosima, 18-24

Young people asked us to think about their social needs beyond the often-imagined craft class in a group day program. They described the jobs and education they hoped to pursue along with the everyday interactions many young people without disability experience as a daily norm.

> "It's not just activities and community experiences, it's a livelihood. It's the difference between me being able to make a living and an income and supporting myself

[8] United Nations (1989) Convention on the Rights of the Child. Article 12.

> somewhat financially on my two feet and not being able to do that. It's the difference between me getting to explore or be hopeful of becoming somewhat educated or having skills to speak and talk and communicate and experience life like a normal human being." - Silvia, 18-24

Silvia, who is legally blind, also described a reality where she might need to weigh the merit of visiting family or friends versus accessing university.

> "I shouldn't have to contemplate going out or seeing my brother, who lives 30 minutes away, or visiting a friend, or accessing university one day, because it's so much effort and so much mental fatigue that comes with that, without the right supports. As soon as you get the right supports, I can do amazing things, and it gives me so much more confidence to be in my own skin." - Silvia, 18-24

Under a human-rights model of support, these are not choices that children and young people with disabiltiy and their families should be faced with.

Solution: Establish a dedicated Transport and Individualised Support Fund to ensure mainstream services are genuinely accessible to children and young people with disability

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Following cuts to NDIS funding for social, economic and community participation, children and young people with disability face increased barriers to accessing mainstream services and participating in their communities. As highlighted in the preceding quotes from young people with disability, access to transport and individualised support is essential to ensuring their right to participate on an equal basis with others.

CYDA calls for the establishment of a dedicated funding stream for transport and individualised support to bridge the gaps left by NDIS funding cuts and ensure mainstream services are genuinely accessible and inclusive.

This could initially be funded through the new Inclusive Communities Fund (ICF). However, to ensure these supports remain available beyond the life of the ICF, sustainable, long-term funding arrangements must be established, including through local councils and other government funding mechanisms.

As well as their rights to full and equal participation under the UNCRPD, children and young people with disability also have a right to:

7. a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community; and
8. effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social

integration and individual development, including his or her cultural and spiritual development[9]

The government's Inclusive Communities Fund, providing $200 million over three years for capacity building in community organisations, is not sufficient to ensure children and young people with disability are afforded these rights.

Capacity building for mainstream organisations to include children and young people with disability is also not adequate to meet their individual needs when participating in their community.

The current system of supports and services, while welcome, is not agile and responsive to the fluctuating and evolving needs of young people with disability. Many of them are making do via their own adaptations. They are concerned that the changes to the NDIS will further constrain their independence, skills and choices, forcing them to put further adaptations in place and make hard choices about their support.

They are anxious about being able to access education, work, and their community in the same ways as their peers without disability, something that they have a right to. And critically, they are deeply concerned about the impact to their mental health and wellbeing, and that of the wider disability community.

[9] United Nations (1989) Convention on the Rights of the Child. Article 23

Conclusion

This report has detailed the key issues and suggestions raised by ten young people in a two-hour focus group run by CYDA in May 2026.

Section one of the report outlined young people's reactions to the proposed changes to three key areas of the NDIS.

First, young people outlined an overall level of mistrust in a standardised assessment tool being used to determine eligibility for the Scheme. They noted as key concerns the inability of static metrics to capture complexity in lived experience, reliance on self-knowledge, limitations in recognising fluctuating capacity, and no process for capturing existing adaptations.

Second, young people reflected on cuts to social, economic, and community participation funding. Their concerns centred on not being able to access school, higher education, and work, losing the skills and independence they have gained, fears for safety, declining mental health, and worry for others in their community.

Third, the four participants aged 15-17 considered the changes to the definition of permanence for NDIS eligibility. They were worried about lack of choice in treatment options, the cost, safety, and mental health implications of needing to try all available treatments, who decides the definition of appropriate treatment, and how consent would be considered.

Section two of the report presented the insights arising from a deeper thematic analysis of the focus group data, with four solutions proposed to correspond to each insight.

The first insight was the profound concern for the harm that could be caused by these reforms, with the solution being no-gap safeguards and complaints mechanisms.

The second insight was a sense of lost connections and fear for mental health. The solution presented was new place-based (including online), peer-led support streams for key stages of development and transition.

The third insight was the misalignment between lived experience of functional capacity and the government's use of the concept, with a solution being to use co-design methods to develop all new support streams.

The fourth and final insight was the lost skills and independence that would lead to hard choices for children and young people with disability. The solution presented was new funding streams for transport and individualised support in mainstream services.

Children and Young People with Disability Australia
Suite 8, 134 Cambridge Street Collingwood VIC 3066
PO Box 172, Clifton Hill VIC 3068

Phone 03 9417 1025 or
1800 222 660 (regional or interstate)
Email info@cyda.org.au
ABN 42 140 529 273

Facebook: www.facebook.com/CydaAu

Instagram: cydaaus

cyda.org.au

