

Survey Factsheet

Released 26 May 2025

About the survey

From 7 to 19 May 2025, <u>Children and Young People with Disability Australia</u> (CYDA) conducted a survey to gather feedback about NDIS eligibility reassessments from young people with disability and their parents and caregivers.

Content note: this factsheet contains references to ableism and suicide.

Who we heard from:

We received 222 responses over 10 days. Of these:

- 71% (197 responses) were parents and caregivers, 92% of whom were caring for a child or young person aged 0 to 25 who was an NDIS participant
- 9% (25 responses) were young people with disability aged 25 or under, 74% of whom were NDIS participants or applicants
- Common disabilities across both groups included Autism, ADHD, intellectual disability, psychosocial disability, physical disability, and others

Fifty respondents (23%) had received an eligibility reassessment letter (75% within the past six months). Seventy-six per cent of children and young people who received letters had Autism.

Following their reassessment:

- 22% were removed from the NDIS
- 26% had their funding reduced or services cut

More than half of those who received a letter (61%) were parents of children aged nine or under. Of these, following reassessment:

- 36% were removed from the NDIS
- 14% had their funding reduced

Key issues raised by respondents

The survey asked respondents to share issues they had experienced with the current eligibility reassessment process.

Removal and loss of supports without clear reasons

Nearly half of respondents (48%) who underwent reassessment said they were removed from the NDIS or had funding reduced. Of these, many had concerns with the process:

- 22% said they felt unheard throughout the process, including due to a lack of consultation, denied requests for more time or information, and ignored evidence
- 15 respondents said their supports were cut despite providing more evidence

The process feels unfair or unreasonable

Nearly all respondents (99%) responded 'no' (70%) or 'unsure' (29%) when asked if they felt the process for reassessing eligibility is reasonable or fair. The 'no' response rate was higher for those who had received a reassessment letter (89%).

- 48% pointed to inconsistent implementation of reassessments, a lack of opportunity for appeal, and not enough time to provide additional evidence
- Some said they spent time and money gathering evidence, only for NDIA staff to not read or ignore it

The process is unclear and confusing

Only 6% of participants answered 'yes' when asked if the reassessment process is clear and easy to understand. Respondents pointed to a lack of information and communication, unresponsiveness to requests, a lack of clarity around timelines, outcomes and required evidence, and conflicting or deliberately vague information.

Of the 50 respondents who received a reassessment letter:

- 70% said it was not clear what 'additional evidence' they needed to provide.
- Some said their request for more information about evidence requirements was not responded to on time, or did not result in clear information

Poor treatment by NDIS staff

Twenty-six respondents reported staff being abusive, condescending, dismissive, rude, or ableist and lacking empathy. Others said staff showed limited understanding of disability and used deficit language.

I was told my significantly disabled son would grow out if his autism and didn't need therapy. I fear that if he is reassess they will try that again (Parent/caregiver of child with disability aged 9 or under)

The emotional toll is severe

Respondents overwhelmingly reported feeling worried (70%), scared (51%), and confused (47%) by the reassessment process. Open-text responses described feeling angry, frustrated, stressed, powerless, abandoned, and even suicidal.

"Suicidal - like I am having my disability used against me and my boys are going to suffer as I am not prepared" (Parent/caregiver of a young person with disability, 18-25 years)

When asked why they felt this way:

- 48 respondents pointed to the impacts of reassessment and a fear of removal from the NDIS
- 26 respondents pointed to the unfairness of the process
- 18 respondents pointed to the burden on families and other systems that would result from being removed from the NDIS or having funding cut without alternative supports available
- 17 respondents pointed to poor treatment and a lack of understanding of disability by NDIS staff

Suggestions for improvement by respondents

Many survey participants had constructive ideas for improving the eligibility reassessment process.

Clear, timely and accessible communication

There was a strong call for clearer, more direct communication in accessible formats and with adequate notice. Respondents recommended:

- Explaining what evidence is needed
- Explaining what funding is for and amounts
- Giving clear timeframes and outcomes
- Providing tools like evidence checklists or standard forms to track the process
- A straightforward appeals process
- Timely provision of Notice of Impairments

Fair and more transparent assessment process

Respondents said they want a process that is consistent, evidence-based and accountable. Key suggestions included:

- Longer timeframes to gather and submit evidence
- Covering some or all costs associated with providing evidence
- Providing public standardised criteria explaining how decisions are made
- Basing decisions on provided expert evidence (rather than non-expert or subjective assessments)
- Reducing wait times for assessments
- Giving a notice period before rendering participants ineligible
- Co-designing the process with people with disability

Staff training and cultural change

Respondents emphasised the need for NDIS staff to be better equipped to work with people with disability in a respectful and informed way. They called for:

- Trauma and disability-informed staff training
- Empathetic and compassionate communication with participants and families
- Reassessment decisions to be made only by those with professional knowledge and/or lived experience

Person-centred and individualised support

Respondents said they wanted a process that recognised the diverse and complex needs of children and young people with disability. A one-size-fits-all approach was seen as ineffective. Suggestions included:

- More flexible communication and assessment options, including face-to-face appointments when needed
- A dedicated complex case support unit

Broad systemic changes

Twenty-four respondents questioned the need for reassessments altogether, particularly for people with permanent disability, and argued that once eligibility is established, it should not be repeatedly challenged.

Other systemic suggestions included:

- Stopping or limiting reassessments for those with permanent disability
- Improving coordination between the NDIS and healthcare professionals, coordinators, and assessors to reduce the administrative burden on participants
- Prioritising continuity of support, like a consistent caseworker, to improve personalised support
- Making sure NDIS resources are distributed fairly; three responses were concerned the 'wrong' people were getting support while others missed out

A final note

CYDA acknowledges and appreciates the many people who took the time to complete the survey and share their experiences. Their voices and perspectives are at the heart of CYDA's advocacy.

It calls on the NDIA to respond to community concerns and implement suggested improvements to the eligibility reassessment process.

A full survey report will be available soon.

Visit www.cyda.org.au for more information.

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