NDIS eligibility reassessments: Views of children and young people with disability, parents and caregivers

Summary of survey responses collected May 2025



Contents

Contents	2
About this report	3
Background	4
Introduction	4
Key messages	7
Align the reassessment process with effective and accessible Foundational Supports	7
Redesign a transparent, fair process for reassessments	7
3. Communicate in a clear, timely, and accessible manner	7
4. Clearly define what constitutes additional evidence a how it will be assessed	anc 8
5. Provide training and additional time for NDIA staff to deliver person-centred and individualised approaches	
6. Provide disability training to NDIA staff	8
Key issues	9
Reduction of supports and removal from the NDIS	9
The reassessment process is not reasonable or fair	.11
The reassessment process is not clear or easy to understand	. 13
It is not clear what additional evidence means	15
Worry, fear and confusion about the process	16
Poor treatment, ableism and lack of disability knowledge from NDIA staff	
Impact on people with intersectional experiences	19
Other issues: trauma, cost and support	21
Suggestions for improvements	22
Appendix A: Who took the survey?	26
Appendix B: Social media summary	28

About this report

Authors:

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

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

Dr Liz Hudson (she/her), CYDA Policy and Research Manager

Lived Experience Review:

Rosie Putland, CYDA Community Engagement Coordinator

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."

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.

Thanks:

CYDA acknowledges the experiences of children and young people with disability, their parents and caregivers and appreciates their time to complete this survey. Their voices and perspectives are at the heart of designing CYDA's advocacy and informing our messages to government.



Content warning: This report references systemic neglect, discrimination, ableism, abuse and suicide.

Background

An eligibility reassessment is a check to make sure NDIS participants still meet the requirements to receive NDIS funding. According to NDIS guidelines, the National Disability Insurance Agency (NDIA) can reassess eligibility if they have evidence suggesting an NDIS participant may no longer meet one or more of the eligibility criteria. This could include the residence, disability, or early intervention requirements.

In late 2024, the NDIA began conducting significant numbers of eligibility reassessments. It is estimated that over **1200 reassessments are being conducted weekly**. Of these, 48 per cent (or approximately 600 participants each week), are having their NDIS access revoked.²

Eighty per cent of those receiving reassessment letters are children aged five to nine. The remaining 20 per cent are from other groups of participants, across a range of disabilities.

Participants originally had 28 days from receiving a reassessment letter to provide additional evidence. In February 2025, the NDIA extended the time for participants to provide additional evidence to 90 days.³

Introduction

Children and Young People with Disability Australia (CYDA) are the national representative organisation for children and young people with disability aged 0 to 25 years. 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.

On 7 May 2025, **CYDA launched a survey to gather feedback about NDIS eligibility reassessments** from young people with disability, their parents and caregivers.⁴

Survey questions were designed to measure our disability community's experience of, and views on, eligibility reassessments, as well as gain insight into potential improvements to the process.

¹ NDIS (2025) What happens if we check your NDIS eligibility? | NDIS.

² Every Australian Counts (2024) <u>Growing Concern Regarding Increased Eligibility Reassessment.</u>

³ NDIS (2025) CEO Statement: Listening to the Community - Eligibility Reassessments.

⁴ Survey was open from 7 to 19 May 2025. This report provides analysis of the 222 respondents that completed the survey.

In just ten days, **222 responses were received from across Australia**.⁵ Twenty-five per cent of respondents had received an eligibility reassessment letter, and shared about the experience and outcome as well as general views on the process and how it could be improved.⁶ Seventy-one per cent had not received an eligibility reassessment letter, and shared general views on the process and how it could be improved.⁷

Seventy-one per cent of respondents were parents and caregivers of children and young people with disability. Of these respondents, 92 per cent were caring for a child or young person who was an NDIS participant. The most common disability type of the children they cared for was Autism (73 per cent) followed by ADHD (52 per cent), the most common age was nine years and under (33 per cent), and the most common gender was boys (57 per cent). Nineteen per cent were from a non-metropolitan area (not from a capital city), 11 per cent identified as culturally and linguistically diverse, seven per cent as Aboriginal, and six per cent as LGBTIQA+.

Nine per cent of respondents were young people with disability under the age of 25. Of these respondents, ¹⁰ 74 per cent were NDIS participants or applicants. The most common disability type was physical disability (54 per cent), then Autism (50 per cent), and psychosocial disability (50 per cent). The most common gender was women/girls (37 per cent). Fifty per cent identified as LGBTIQA+, 29 per cent were from a non-metropolitan area, and a quarter were culturally and linguistically diverse.

Twenty-five per cent of respondents had received an eligibility reassessment letter. Of these respondents,¹¹ 89 per cent were received by parents/caregivers, and 61 per cent of these were for children nine years and under. Seventy-six per cent of the children and young people were Autistic, and 57 per cent were ADHD. Eleven per cent were Aboriginal, 11 per cent were from a non-metropolitan area, two per cent identified as LGBTIQA+, and two per cent as culturally and linguistically diverse. Eight per cent of letters were received directly by young people with disability, of which 75 per cent were Autistic, 75 percent identified as LGBTIQA+, and 75 per cent were culturally and linguistically diverse.

Of the respondents who received a letter, **71 per cent had received their letters in the past six months**. While 28 per cent had the extended 90 day period to provide

⁵ 32 per cent were based in Victoria, 19 per cent in Queensland, 18 per cent in New South Wales, 11 per cent in Western Australia, nine per cent in South Australia, six per cent in Tasmania, six per cent in the Australian Capital Territory. There were no responses from the Northern Territory.

⁶ The percentage of 25 per cent is based out of a total of 198 responses (24 skipped the question).

⁷ Out of a total of 198 responses (24 skipped the question).

⁸ Out of a total of 190 responses (7 skipped the questions).

⁹ Disability type questions were asked in a "tick all that apply" format, meaning that several respondents selected a combination of disability types.

¹⁰ Out of a total of 24 responses (1 skipped the questions).

¹¹ Out of a total of 46 responses (4 skipped the questions).

additional evidence, 24 per cent only had 28 days. A further 28 per cent were unsure how long they had to provide additional evidence, indicating that the process is not clear or easy to understand. Twenty-two per cent were removed from the NDIS following reassessment. A further 26 per cent had funding drastically cut or services removed. For children nine years and under, 32 per cent were removed.

Responses showed that **children and young people who were Autistic, from diverse backgrounds**, and **First Nations children**, were likely to be **disproportionately impacted by reassessments**. Autism was prevalent in respondents who received a reassessment letter, and even more so in respondents from diverse backgrounds. First Nations children and young people in particular were nearly twice as likely to have received a reassessment letter (42 per cent compared to 23 per cent overall responses), and outcomes of reassessment letters were removal, reduction of funding, or uncertain. One hundred per cent said the reassessment process was not reasonable or fair.

A more detailed breakdown of survey respondents can be found at **Appendix A**.

Direct quotes from respondents are indented, italicised and in inverted commas, anonymised to protect privacy, and minimally modified for brevity and/or clarity.

Percentages are calculated based on number of responses to individual questions.

Thematic analysis was used to analyse open-ended responses. Qualitative responses were coded and then grouped into broader themes and refined through a peer review process that checked for accuracy. This process has led to a coherent and meaningful account of respondent lived experiences presented in this report.

Next steps

CYDA presented the initial survey results directly to the NDIA at a two-hour co-design workshop on 26 May 2025, to make sure that the NDIA is hearing directly from people with lived experience about the process and what improvements could be made. This survey is part of CYDA's ongoing commitment to understand how children and young people with disability, and their families and caregivers experience reform in the sector.

¹² 76 per cent of children who received letters were Autistic. Autism was also more prevalent in diverse groups (in parent/caregiver responses, 100 per cent of LGBTIQA+ children and young people they cared for were Autistic, 92 per cent of First Nations children and young people, and 81 per cent of culturally and linguistically diverse children and young people). This is compared to 73 per cent of overall parent/caregiver responses and 50 per cent of young people responses.

¹³ Out of five First Nations responses, one was removed from NDIS, one was unsure, and three had funding reduced.

¹⁴ Out of eight First Nations respondents.

Key messages

These key messages are intended to improve the NDIS eligibility reassessment process, and are directly developed from the survey responses provided.

1. Align the reassessment process with effective and accessible Foundational Supports

CYDA recommends that no child or young person has their funding reduced or removed until Foundational Supports are put in place. Parents and caregivers of children nine years and under are concerned about being removed from the NDIS with no alternative supports or pathways, particularly for young children who are Autistic. They note the detrimental impact of removal with no alternatives on their children and families. Some suggested that the process was being conducted back-to-front, with reassessments happening before Foundational Supports had been designed and implemented. Putting in place quality and effective Foundational Supports is an essential first step to ensuring that no child falls through the cracks, and managing associated risk across multiple systems (health, welfare, education, housing).

2. Redesign a transparent, fair process for reassessments

CYDA recommends the NDIA undertake a co-design process to provide a consistent, evidence-based and transparent approach to reassessments. Children and young people with disability, their parents and caregivers do not feel that the reassessment process is transparent, fair or reasonable. There is confusion, fear and worry around who is reassessed, why, and how. Many conveyed distrust in the process, feeling that decisions were arbitrary, subjective, and inconsistent. A transparent, fair approach should include longer timeframes to gather and submit evidence, cover the costs of providing evidence, provide public standardised criteria explaining how decisions are made, base decisions on expert evidence (not subjective assessments), reduce wait times for assessments, provide notice before rendering participants ineligible, and be co-designed with people with disability.

3. Communicate in a clear, timely, and accessible manner

CYDA recommends the NDIA provide participants with up-to-date, clear and accessible information on reassessments to build trust and positive engagement. Young people with disability, families and caregivers, have shown confusion, worry and fear toward reassessments. As part of design and implementation, NDIS participants should be well informed about how reassessment processes work, including timeframes. With ongoing reforms, it is important that information is provided accessibly. This includes consideration of communication channels, as well as formats. Participants must receive information directly to ensure they are clearly informed of changes that have a significant impact on their lives.

4. Clearly define what constitutes additional evidence and how it will be assessed

CYDA recommends the NDIA provide participants with clear, user-tested requests for additional evidence, and specify how evidence will be assessed. Currently most children and young people with disability, their parents and caregivers do not feel that it is clear what they need to provide as additional evidence for reassessments. Participants frequently found that NDIA staff assessing their Plans did not read the expert advice and reports provided, and displayed limited disability knowledge. This is despite going to lengths to ask for clarity, and providing costly reports based on medical and therapeutic expertise. Ensuring that people being reassessed understand what evidence is required, and that reassessments are clearly informed by the evidence provided, is vital to a timely, effective and fair process.

5. Provide training and additional time for NDIA staff to deliver person-centred and individualised approaches

CYDA recommends the NDIA provide staff training on intersectional and complex support, linked to performance outcomes. Reassessments are having a disproportionate impact on people with intersectional experiences, particularly First Nations children, children who are Autistic, and from diverse backgrounds. The reassessment process must be responsive to individuals across different identities, life experiences, and geographical locations rather than a one-size-fits-all approach. NDIA staff should be trained in communicating flexibly through an individualised, personcentred approach. Training should be linked to performance outcomes and evaluated through participant feedback, as well as measures such as demonstrated understanding of disability rights, use of trauma informed responses, and respectful communication. NDIA must ensure adequate time is provided to staff to read and process the additional evidence that has been requested.

6. Provide disability training to NDIA staff

CYDA recommends the NDIA provide trauma-informed disability training to staff, linked to performance outcomes. NDIS participants have experienced abuse, discrimination and humiliation by NDIA staff in frontline and decision-making roles. They reported that NDIA staff took a deficit approach and told them their children would "grow out of" their disability – a view repudiated in medical and peer-reviewed disability evidence. This is a serious human rights violation and needs to be urgently addressed by the NDIA. It is crucial that staff with decision-making power have disability-related knowledge and awareness. A key first step is to provide trauma-informed disability training to all NDIA staff to promote awareness and practice of rights-based approaches to disability that acknowledge social barriers rather than placing blame on the person with disability themselves. This training should be linked to performance outcomes and include measures of evaluation for effective uptake.

Key issues

The following is a summary of key issues identified by survey respondents.

Reduction of supports and removal from the NDIS

Of the respondents who received an eligibility reassessment letter, **22 per cent had been removed from the NDIS** following their reassessment. A further **26 per cent had their funding drastically cut or services removed**. Two respondents were told that existing supports in their Plan fell under "parental responsibility":

We were told that most of what we requested were not covered under my child's impairment even though they had been previously covered. We were told that mainstream supports were better suited even though there was no mainstream service, we were told that because my son was under 18 that everything was deemed parental responsibility. I was told that if I couldn't fulfill my parental responsibility that I would be reported to Department of Children Services (Parent/caregiver of young person with disability, 15-17 years)

Sixty-one per cent of reassessment letters were received by **parents/caregivers of children with disability nine years and under.** Of those, 75 per cent were received in the past six months (compared to 71 per cent of letters in total). Thirty-six per cent only had 28 days or less to provide additional evidence (compared to 24 per cent of letters in total).

A deeply concerning finding was that 32 per cent of children nine years and under were removed from the NDIS, and a further 14 per cent had their funding severely reduced. This was higher than overall survey respondents who received a letter and were removed from the NDIS (22 per cent), mirroring wider evidence that children nine years and under are more likely to be removed from the Scheme following reassessment. NDIA have reported that in the two months between 1st August and 30th September 2024, 65 per cent of those removed from the Scheme after undergoing eligibility reassessment were aged seven to eight years old. 16

Very harsh for young children, the criteria are very hard to obtain in such a short window of time when they allowed roll overs for over six years, and then only gave 21 days notice (Parent/caregiver of child with disability, 10-14 years)

Twenty-two per cent of overall respondents **felt unheard** throughout the process, including: having no opportunity for consultation, being denied requests for more time

¹⁵ Out of a total of 46 responses (4 skipped the question).

¹⁶ Community Affairs Committee, 6 November 2024. Question on notice no. 457.

and/or clearer information, having the reports they provided as evidence ignored, and feeling the specificities of their case were not taken into account.

A troubling trend was the **removal of participants from the NDIS**, or severe cuts to their support, despite meeting the requirements for evidence. Thirty per cent (15 responses) of those who received a letter expressed bewilderment that their supports were cut despite providing more evidence, and with no recourse to alternative supports:

No understanding of why some supports were given, and some taken away. The assessment in Feb was the first one since his formal diagnosis, yet he now receives less funding than before his diagnosis. We also had at least triple the evidence than our prior review, clearly stating his decline. We were advised that he would not receive any support unless he had a diagnosis, yet somehow he was funded better without one?!?! (Parent/caregiver of child with disability, nine years and under)

[Reassessments] should be fair and balanced if they go ahead - based on compassionate practitioners preferably with wide disability experience.

Other pathways should be set up for help before a participant leaves the NDIS or they risk falling down where they can't get help (Parent/caregiver of child with disability, 10-14 years)

A further **22 per cent were still waiting for the outcome** of their reassessment, or the outcome was unknown.

Twenty per cent remained eligible with no reported changes to their Plans.

A respondent who expressed worry and fear about the prospect of removal due to the eligibility reassessment process noted how vital NDIS supports were for their son:

The NDIS has been life changing and life affirming for our son. It has supported him to work, to increase social participation and to strengthen a healthy lifestyle (Parent/caregiver of young person with disability, 18-25 years)

Figures provided by NDIA in a recent Senate Budget Estimate hearing reported that in the week ending 28 September 2024 1,200 eligibility reassessments were undertaken. Of those, 58 per cent were removed from the Scheme, while a further 33 per cent had their eligibility status changed - most likely reflecting a reduction in Plan funding. While NDIA have provided the overall value of Plans removed from the Scheme at \$124,999,750 between 1 July and 30 September 2024 the have not provided the value of Plan reduction, making it difficult to track the scale of the impact of funding cuts on NDIS participants.

10

¹⁷ Community Affairs Committee, 6 November 2024. Question on notice no. 459.

¹⁸ Community Affairs Committee, 6 November 2024. Question on notice no. 456.

The reassessment process is not reasonable or fair

Ninety-nine per cent of survey respondents¹⁹ responded either "no" (70 per cent) or "unsure" (29 per cent) when asked "Do you feel that the process for reassessing NDIS eligibility is reasonable and fair?" One respondent said "yes", and one preferred not to say.

For those respondents who had received a reassessment letter, the rate responding that the process was not reasonable or fair was higher, at 89 per cent (compared to 70 per cent overall).²⁰ None of the respondents who had received a letter said the process was reasonable or fair.

When respondents were asked to share any issues they experienced with the reassessment process, the **responses overwhelmingly showed that they found the process unreasonable and unfair**. Forty-eight per cent (61 responses) pointed to adhoc, inconsistent implementation of reassessments, including subjective assessments with no chance for appeal. They also emphasised that the time given to provide additional evidence was not feasible.

Because I could not get info in 28 days and had to wait for specialist, Son was failed by NDIS with no grounds for appeal (Parent/caregiver of child with disability, 10-14 years)

90 days is not long enough for reassessment to be complete including wait for appointments and then the wait for reports. Put the families under a lot of pressure. Plus if you don't get the documents in time, you lose your current services and once NDIS has approved the paperwork, you will have to go back on the wait lists to access these services (Parent/caregiver of child with disability, nine years and under)

A key issue was that NDIA staff (mainly assessors) were **ignoring evidence requested** such as medical reports, that had come at a high cost for participants to provide—in both time and money.

Having to get expensive reports and assessments and when contacted told no we haven't read them. (Parent/caregiver of young person with disability, 18-25 years)

Lack of contact, lack of information about the status of any requests for change. Spending money on letters and reports which takes away from the child actually attending therapies and then being told that those reports haven't been read or seen (Parent/caregiver of child with disability, 10-14 years)

11

¹⁹ Out of a total of 126 responses (96 skipped the question).

²⁰ Out of a total of 35 responses (15 skipped the question).

A small number of respondents pointed to **unfairness in terms of participants and providers**. Similar sentiments can be noted in some of the social media responses at **Appendix B**.

Two per cent (three responses) were concerned with who was receiving NDIS supports. They indicated that there were people who were not vulnerable being funded, leading those most in need to miss out. One of these respondents suggested that parents should be supporting their non-vulnerable children instead of relying on the NDIS. Another suggested that paying family members to support their own family was a misuse of funds.

Two other responses pointed to issues with the lack of accountability of providers.

A futher two per cent (three responses) suggested that those without permanent disability including young children should be reassessed, so that the Scheme could focus on those with permanent disability:

For children who need early intervention and don't have ongoing disability it is good to reassess as won't need lifelong support from NDIS (Parent/caregiver of child with disability, nine years and under)

Case Study: Inconsistent outcomes across cases

A parent of an Autistic girl who is nine years old or under from Western Australia found the reassessment process "unfair and so biased. It depends on who you speak to and what kind of mood they are in as to what funding you receive."

The parent was given 28 days to provide additional evidence after receiving a letter, with an outcome of severely reduced funding "when others with the same or less of a diagnosis received more funding". They felt their evidence and their circumstances were ignored: "Why [do] we need to give reports if they are not even read or considered?". None of the reports provided were taken into consideration and i was told 'parental responsibility' for most things that were requested for by the therapists reports... however we have five kids with disabilities which was not taken into consideration."

The parent felt worried and "afraid they will cut my daughters funding even more and she is already struggling so bad".

To improve the process, the parent asked for "Clear guidelines on funding amounts and the chance to be heard".

CYDA calls on the NDIA to acknowledge evidence provided on request, to be consistent and fair when undertaking reassessments, and to take specific circumstances of participants into account.

The reassessment process is not clear or easy to understand

Ninety-three per cent of survey respondents responded either "no" (66 per cent) or "unsure" (27 per cent) when asked "Do you feel that the process for reassessing NDIS eligibility is clear and easy to understand?" ²¹ Only six per cent responded "yes".

For those respondents who had received a reassessment letter, the rate who responded that the process was not clear was higher, at 77 per cent (compared to 66 per cent overall).²²

Seventeen per cent (21 responses) mentioned in response to the question "what issues have you experienced with the reassessment process" that the **process was unclear and difficult to understand**. Issues ranged from lack of information and communication, unresponsiveness to requests, lack of clarity around the timeline and outcome, conflicting and deliberately vague information.

They are deliberately vague and unclear. They do not explain the legislation. It's a fishing expedition and if you don't know your rights and how to get help then they just kick you off because they know you can't stick up for yourself (Parent/caregiver of young person with disability, 15-17 years)

It's an unknown and stressful it's not clear what's happening, what's required and who is affected (Parent/caregiver of child with disability, 10-14 years)

When asked what could make the process clearer, respondents offered a range of suggestions.

Thirty-nine per cent (33 responses) said that **the target cohort for reassessments needed to be clearer**—who was being reassessed, and why it was needed. These respondents expressed confusion as to why people with lifelong disability were being reassessed, and why people were losing support despite providing the required evidence. Others asked why there were so many children receiving letters. Some thought that the reassessment criteria and levels of funded supports seemed arbitrary, sharing experiences of complex disability receiving less than others, and of the wrong supports being funded.

They need to stop asking for reports to determine if your child's "condition" has improved. There is no cure for cerebral palsy, so his diagnosis will not change! It is PERMANENT!! LIFE LONG!! (Parent/caregiver of young person with disability, 18-25 years)

²¹ Out of a total of 126 responses (96 skipped the question).

²² Out of a total of 35 responses (15 skipped the question).

One of my children (5 -asd 3) is marked for eligibility reassessment and not even the LAC is able to tell me why. We did a change in situation reassessment mid-2024 and by Dec 2024 he was "pending reassessment" and I've heard nothing. It's so stressful (Parent/caregiver of child with disability, nine years and under)

A key sentiment expressed in responses was that current reforms including reassessments were making **NDIS** participants feel less confident in the Scheme:

When we were being moved from state disability services to NDIS, I was told my sons support through NDIS was now secure for life. If I drop dead tomorrow, I'm unclear if he has the safety net of ongoing NDIS or will he end up being caught in what feels like a cost-saving exercise by government. I'm worried for his future and feel less confident in the NDIS. My son has always, and will always, live as a disabled person. This won't change. He will always have a need for disability specific support and services. I don't believe he/we should have to live with the threat of proving his eligibility (Parent/caregiver of young person with disability 18-25)

Thirty-three per cent (28 responses) asked for **more clarity on the evidence required**, including giving specific examples, parameters and criteria for what they needed to provide. They noted that the requirements were unclear, and it was hard to prepare for reassessment.

Very specific examples and requests for information, reports etc need to be clear and listed on the letter, with a clear due date (Parent/caregiver of child with disability, 10-14 years)

Unclear as to what information/proof of disability they want and not enough time to obtain said information/proof (Parent/caregiver of child with disability, nine years and under)

It is very hard to prepare as there are not clear requirements, standardised documentation requirements, how much to prepare and clarity on impact of language which can effect outcome (Parent/caregiver of child with disability, 10-14 years)

Other suggestions included:

- more clarity on the process (18 responses, or 21 per cent) including how it is done, clear timeframes, and processes for appeal
- better support with the process (13 responses, or 15 per cent), including advice on what to provide, consultation, and extra support when needed especially to accommodate access needs
- better and more communication about the process (11 responses, or 13 per cent), including regular updates, responsiveness to requests for changes, and making sure information is up-to-date (such as on the website)
- more time to provide evidence and giving more notice of reassessment (3 responses, or four per cent).

A further four responses said that everything needed to be changed, referring to the whole NDIS ecosystem.

Overall, survey responses noted the importance of clear information provided to the community in a way that is timely and accessible for all those who may be impacted.

My son underwent eligibility reassessment with NO communication from NDIS at all. I didn't know it was happening. I wasn't contacted at all - by letter, email, phone or via a key worker (Parent/caregiver of child with disability, nine years and under)

Work with parent and if I can prove my daughter was on waiting lists for specialist, to allow time for that to happen before just cutting her off with hardly any notice (Parent/caregiver of child with disability, 10-14 years)

In a separate question about how respondents preferred to be contacted and consulted by government, 65 per cent preferred email, 33 per cent preferred webinar, 29 per cent preferred small online groups, 26 per cent preferred website, 24 per cent preferred social media, 21 per cent in person small groups, and 14 per cent public meetings. This demonstrates a range of preferences, and highlights that it would be worthwhile for the NDIA to assume a person-centred approach by consulting with participants about the types of communication they prefer for reassessments.

It is not clear what additional evidence means

As highlighted above, a specific issue that emerged from the question "what needs to be clearer" was the need for more clarity around evidence required. Of the respondents who received an eligibility reassessment letter, 70 per cent said it was not clear what additional evidence they needed to provide (57 per cent said "no" when asked whether it was clear, and 13 per cent were "unsure"). Only 28 per cent said that it was clear what additional evidence they needed to provide.

I want clarity. I want written information, I want them to understand they should be speaking to me the participant and should communicate directly about what exactly they need from me in order for me to be able to keep access to my funding (Young person with disability, 18-25 years)

Respondents noted that even where they had actively sought information about additional evidence, their requests were not responded to in a timely manner and did not provide clear information.

I'm told I need more evidence - when I ask what evidence they cannot provide me with any sort of clear answer as to what treatments they are specifically wanting me to list as having completed (Young person with disability, 18-25 years)

Worry, fear and confusion about the process

Survey responses indicated significant worry, fear and confusion about NDIS eligibility reassessments.

When asked how they were currently feeling about reassessments, **70 per cent of respondents said they were worried**, 51 per cent said they were scared, and 47 per cent said they were confused.²³

Only five per cent of respondents said they were curious, while four per cent felt neutral. **None selected a "positive" feeling response**.

Twenty per cent of respondents (25 responses) chose to express different feelings to the options presented, using the "other" open text box. Of these responses, 64 per cent (16 responses) reported feelings of anger, including fury, frustration, disgust, annoyance and stress. Forty per cent (10 responses) reported feelings of hopelessness, including feeling abandoned, powerless, disappointed, disheartened, exhausted and in the dark, with two reporting feeling suicidal. 20 per cent (5 responses) reported feeling terrified, including feeling traumatised and scared.

For those who received a reassessment letter,²⁴ 57 per cent said they were worried, 57 per cent were scared, and 46 per cent were confused. Three per cent were neutral.

Thirty-five per cent of respondents who received a reassessment letter (12 responses) chose to express different feelings using the "other" box.²⁵ Sixty-six per cent of those (eight responses) reported feelings of anger including frustration and stress. Seventeen per cent (two responses) directly mentioned feeling suicidal, **meaning that the two responses indicating suicidal thoughts in the overall responses were from respondents who received letters.**

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 young person with disability, 18-25 years)

The NDIS is killing me and my kids through neglect and apathy (Parent/caregiver of child with disability, nine years and under)

During a recent Budget Estimates hearing, NDIA was asked to report on the number of participants who died by suicide from 2022 until the present.²⁶ The question has not

²³ Out of a total of 126 responses (96 skipped the question). Respondents could pick more than one feeling response.

²⁴ Out of a total of 35 responses (15 skipped the question).

²⁵ Out of a total of 35 responses (15 skipped the question).

²⁶ Community Affairs Committee, 6 March 2025. Question on notice no. 391 (unanswered).

yet been answered. Loss of NDIS funds and difficulties navigating an adversarial process has previously been linked with suicide.²⁷

A further 12 responses to the question "what issues have you experienced with the process" explicitly mentioned the negative emotional impact of the process including stress, worry, distress and fear.

When asked why they felt this way, 38 per cent (48 responses) focused on the **detrimental impacts of reassessments and fear of removal from the NDIS**, with a focus on the harms and risks this could cause participants, especially children. Many felt reassessments were undertaken with the goal of cost cutting, not in the interests of the best care and supports for participants. Many shared that the reassessment process was detrimental to the stability and needs of their families and children.

My son requires his NDIS to get him the support he needs. Without this his whole life of developing the skills is compromised affecting his future significantly (Parent/caregiver of child with disability, 10-14 years)

Twenty-one per cent (26 responses) focused on the **unfairness of the process**, including the arbitrary and inconsistent nature of the reassessments as to who received letters, how evidence was assessed, timeframes and outcomes.²⁸

There seems to be no rhyme or reason as to who is chosen for these reassessments, and there's no transparency for participants or their families as to what the process actually involves (Young person with disability, 18-25 years)

A further 14 per cent (18 responses) focused on the **burden on families**, **as well as other systems** such as the health and education systems. This burden came from the outcome of removal from the NDIS or loss of funding with no alternative supports or safety net, but also from the reassessment process itself which was costly for families.

There's so many families with kids like mine (autistic and ADHD kids who otherwise have no intellectual disability) who get their funding cut because apparently things like psychologists are "covered under Medicare". Except they aren't. Mental health support for our kids is impossible unless you are rich (Parent/caregiver of child with disability, nine years and under)

It is worth pointing out that the NDIA is yet to answer a question asked at a March 2025 Budget Estimates hearing about risk. They were asked if the Agency considers risk to participants as an outcome of reassessments and whether alternative supports would be made available to participants removed from the Scheme.²⁹

²⁹ Community Affairs Committee, 6 March 2025. Question on notice no. 389 (unanswered).

²⁷ Henriques-Gomes, 2022. <u>'It literally breaks you': fight for denied NDIS support dominates 23-year-old's final months.</u>

²⁸ Out of a total of 126 responses (96 skipped the question).

Thirteen per cent (17 responses) pointed out the **ableism of the NDIS system**, from derogatory and dismissive interactions with staff who did not understand disability and were unqualified to make assessments, to having to fit into a "deficit" model of disability to prove their eligibility.

Ten per cent (13 responses) spoke to the **lack of information and communication**, and a further seven per cent shared feeling helpless, uncertain and a loss of trust.

Because some of these NDIS changes seem to have come out of nowhere and then the goal posts seem to keep moving. It's not clear if we will receive a letter so it feels like waiting for the other shoe to drop. Then if we do I'm not sure how I will go about getting the evidence they ask for and whether this will be sufficient. I keep hearing stories about other people's letters not being clear about what kind of evidence is being requested. It's a horrible way to live.

(Parent/caregiver of child with disability, nine years and under)

I have no certainty. The funding they've given me will mean I cannot go to uni, I am not guaranteed to have their decision reviewed by next semester so I am having to decide to defer. I cannot get transport to get my medications or go to drs appointments etc with the funding I have and I'm worried about what that will mean for my health. And I am scared that I'm losing the little access I have to leaving my house (Young person with disability, 18-25 years)

Poor treatment, ableism and lack of disability knowledge from NDIA staff

Responding to questions about what issues they had experienced and what could be improved, 24 per cent (30 responses) highlighted **negative interactions with NDIA staff**. These included poor treatment: staff being directly abusive, discriminatory, condescending, rude, lacking empathy or making them feel undeserving.

They are frightening, they make you feel you have to speak about your child's deficits in such a negative way and then continually fight for the support they need. They make you feel you don't deserve the help (Parent/caregiver of child with disability, 10-14 years)

Every single person I've encountered within the agency has no clue about disability and uses disability tropes as excuses to refund. The ableist rhetoric has to stop as it's discrimination and extremely offensive (Parent/caregiver of young person with disability, 15-17 years)

There were also concerns about the **lack of disability related knowledge demonstrated by staff involved in assessments**, especially when they used deficit language or told participants they would "grow out of it". This points to the critical need for more staff training and/or employing more staff with professional and lived experience as an exercise in harm prevention.

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[ed] they will try that again (Parent/caregiver of child with disability, nine years and under)

Impact on people with intersectional experiences

Responses were analysed based on demographic background. This revealed two groups likely to be significantly negatively impacted by eligibility reassessments:

1. Children and young people who were Autistic from diverse backgrounds

Autism was high in survey responses, reported at 73 per cent in parent/caregiver responses (related to the children and young people with disability they cared for) and 50 per cent in responses from young people with disability themselves. For respondents from diverse backgrounds, Autism was more prevalent:

- 100 per cent for LGBTIQA+ children and young people with disability³⁰
- 92 per cent for First Nations children and young people with disability, 31 and
- 81 per cent for culturally and linguistically diverse children and young people with disability.³²

The majority of participants being removed from the Scheme through reassessment are children and young people,³³ and NDIA data demonstrates that the primary diagnosis for 78 per cent of participants under 18 is Autism.³⁴ While it has proved difficult to find a breakdown of Scheme removals by disability category, these figures support anecdotal reports in the community that children who are Autistic are more likely to be reassessed. It follows that the increased prevalence of Autism in respondents from diverse backgrounds may mean they have a higher likelihood of being impacted by reassessments.

2. First Nations children and young people with disability

First Nations children and young people with disability could be multiply impacted by reassessments:

• they were nearly twice as likely to have received a reassessment letter (42 per cent compared to 23 per cent of overall responses)

³⁰ Out of 12 respondents (parents and caregivers). A further 75 per cent of LGBTIQA+ young people with disability reported having Autism (based on 12 responses from young people with disability).

³¹ Out of 13 respondents (parents and caregivers).

³² Out of 21 respondents (parents and caregivers).

³³ Hansard, 2024-25, <u>Budget Estimates Committee</u>, see pages 26-30.

³⁴ NDIS, 2033-24, Autism Dashboard.

- Autism was much higher than average (92 per cent compared to 73 per cent)
- a higher percentage of the group were 9 years and under (46 per cent compared to 33 per cent overall)
- more than double were unsure how long they had to provide additional evidence (60 per cent compared to 28 per cent overall)
- outcomes of reassessment were removal, reduction of funding, or uncertain³⁵
- 100 per cent said the reassessment process was not reasonable or fair.³⁶

These intersecting factors mean that First Nations children and young people who are Autistic are at higher risk of reassessment, with the likely outcome of removal from Scheme or reduction of funding.

Case Study: First Nations family "kicked off the NDIS" with no alternative supports

A parent living in regional New South Wales shared their experience of receiving an eligibility reassessment letter from the NDIA in the last 1-3 months. Their child, an Aboriginal boy who is nine years old or under, has a learning disability, ADHD and is Autistic.

The parent felt that both the process for reassessment and the additional evidence being asked for was not clear, saying it was, "Unclear as to what information/proof of disability they want and not enough time to obtain said information/proof".

They also felt the process was unfair and unreasonable and would have preferred "a clear, itemised list of what proof is needed, and instructions on how to get it as well as more time to get the proof".

The process resulted in their child being "kicked off the NDIS". Given Foundational Supports are not yet available, this places this First Nations family in the unacceptable scenario of having no immediate supports for their child with disability.

The parent described their feelings about the experience as "scared", "confused" and "worried", elaborating that this is because "I feel like we risk our children being removed from their supports without any way to stop it".

CYDA calls on the NDIA to ensure First Nations families are not left in a precarious position as a result of the reassessment process, and to provide culturally safe and person-centred supports.

³⁵ Out of five responses, one was removed from NDIS, one was unsure, and three had funding reduced.

³⁶ Out of eight First Nations respondents.

Other issues: trauma, cost and support

In a final open-ended question "is there anything else you'd like to tell us about reassessments", respondents emphasised the **stress**, **trauma and cost that was being caused to families and children**, and the **need to make the process fairer and clearer while providing better support** to those navigating it.

Thirty-one per cent (38 responses) shared the **emotional and financial costs of reassessments**, from putting stress on carers and other systems to dehumanising participants and making them feel like a burden and violating human rights. There were suggestions that the NDIA should cover the costs of reassessments if they were requiring them.

Many felt strongly that **reassessments should be stopped as they were a smokescreen** for a cost cutting exercise and mostly led to removal or reduction of supports, affecting the capacity for actual review and changes to be made to Plans when needed by the participant. The detrimental impact on young children was specifically pointed out.

Some disabilities are for life. Requiring reassessments for something like my son's disability would seem unnecessary. Despite dearest wishes and efforts, the situation difficulties don't go away. They evolve. When funding is reduced some years, we experience regression and challenges. Inconsistency isn't fair. It affects development, capacity of informal supports and their ability to cope, ability to retain the therapists who are the right fit. Most importantly, it impacts the individual's quality of life significantly, and their opportunities to participate in daily life, community and society is severely jeopardized (Parent/caregiver of young person with disability, 15-17 years)

Fifteen percent (19 responses) focused on the **need to make the process fairer**, including questioning why people with lifelong disability should need to be reassessed and asking for stronger accountability on decision-makers as well as quality of supports.

They should be fair and balanced if they go ahead - based on compassionate practitioners preferably with wide disability experience. Other pathways should be set up for help before a participant leaves the NDIS or they risk falling down where they can't get help (Parent/caregiver of child with disability, 10-14 years)

It is being rushed through to save dollars rather than a fair equitable and transparent process (Parent/caregiver of young person with disability, 15-17 years)

A further 13 per cent (16 responses) asked for **better support and communication** to assist with understanding the process and improvements to the system, including more time, person-centred approaches, continuity of care, disability aware staff, and support for disabled carers/parents to understand the process.

Case Study: Out of pocket and removed from NDIS

"I feel completely let down", the parent of a girl who is nine years or under from Brisbane told us. Their eligibility reassessment letter arrived in late 2024 with 28 days to provide additional evidence and resulted in their child being removed from the Scheme. "I was certain it wouldn't be a problem seeing as my child has a permanent, chronic, degenerative [physical] condition, however it was the start of a nightmare".

They felt the process was "confusing and [provided] unclear instructions" and stated that it left them feeling "scared", "confused" and "worried". Providing "clear, definite examples of what needs to be included [and] more time to source [evidence]" would improve the process.

At the conclusion of the reassessment, not only was their daughter left without her disability supports, but the family were out of pocket after sourcing evidence that the NDIA requested and then having no ability to claim these costs. The parent explained they were "not reimbursed for assessments we had done as we were deemed ineligible after providers had been paid from own funds."

CYDA queries why a child with a permanent condition was removed from the Scheme, and calls on the NDIA to provide clear instructions and more time for evidence, as well as reimbursement of costs.

Suggestions for improvements

Despite concerns, respondents had constructive ideas for improving the process.

Twenty-nine per cent (37 responses) suggested that the process could be made fairer and more reasonable through:

- giving a more reasonable timeframe to provide evidence
- making it more transparent, providing a publicly available standardised outline of why/how decisions were made, including the appeal process
- basing the assessment on the evidence provided by experts and reports (rather than non-expert and/or subjective assessment)
- covering some or all of the costs associated with providing evidence
- reducing the waiting time for assessments
- giving a notice period before rendering participants ineligible
- **co-designing the process** with people with disability, adopting a **person-centred aproach** and including a range of **communication options**.

Have the process give more time to gather evidence, FUND the reports needed (I do not have an extra few \$1000+ to pay for multiple reports from multiple therapists) (Parent/caregiver of child with disability, nine years and under)

Transparent information for people/carers to see what the assessment process will be, criteria they will be measured against and ensuring family circumstances are considered. Appeal process to be simple, transparent and timely - currently varied in response. Direct contact options to resolve reasonably (Parent/caregiver of young person with disability, 15-17 years)

Provide a 6 month notice period for those deemed ineligible so that children and young people are not suddenly left without supports but have time to find alternatives or phase some supports out (Parent/caregiver of child with disability, nine years and under)

To have people with actual health and/or disability sector backgrounds determining eligibility rather than bureaucrats going off a list of terms. And having reports that participants have paid money for actually being read (Young person with disability, 18-25 years)

Nineteen per cent (24 responses) **questioned the need for reassessments** altogether, particularly for permanent disability and/or high support needs, arguing that once eligibility is established, it should be guaranteed and not repeatedly challenged.

A reassessment should not be required. You have net criteria and should not be allowing these poor people and families being dragged through this (Parent/caregiver of child with disability, 10-14 years)

I would not have it at all. I think it's unfair that someone who met the criteria for the scheme should be taken off it (Young person with disability, 18-25 years)

Once a person has been diagnosed and is eligible for support, please stop asking for reassessments! It weighs down the person with disability, worries their family so much and creates unnecessary medical/allied health appointments for the completion of forms/paperwork (Parent/caregiver of young person with disability, 18-25 years)

Get rid of it entirely. It goes against the entire purpose of the NDIS Act (illegal? malfeasance? human rights abuse?) to cancel access once it's been granted, because access requires that the person's disability is permanent/lifelong. Not to mention that the "reassessment" is inexpert, unevidenced, unscientific, and unobjective, and ignores all medical/allied health evidence provided (Parent/caregiver of young person with disability, 18-25 years)

Eighteen per cent (23 responses) suggested the process could be made clearer by:

- explaining what is needed for evidence
- explaining what funding is for and amounts
- giving clear timeframes and outcomes

- better, more accessible communication, including ways to track the process such as a clear form to fill out before review, and checklists for what evidence is
- clear appeals process
- timely provision of Notice of Impairments (still not received).

Give a clear, itemised list of what proof is needed, and instructions on how to get it as well as more time to get the proof (Parent/caregiver of child with disability, nine years and under)

Clear guidelines around what makes someone eligible / ineligible (Parent/caregiver of child with disability 10-14 years)

Explain what exactly is needed and given, a reasonable time to have reports etc in (Parent/caregiver of child with disability, nine years and under)

Sixteen per cent (20 responses) recommended more focus **on individual cases and complex needs**, including making sure that parents, caregivers, children and young people with disability were heard. Specific ideas included more **flexible and accessible communication and assessment options**, including the option for face-to-face appointments; and creating a complex case unit. One respondent mentioned parents with disability caring for children with disability as requiring tailored support.

We've never had an in person review with anyone only over zoom. The first person we did our plan with just decided that anything my daughter said at the time was what her plan would be based on. It was ridiculous because my daughter wasn't capable of understanding a lot of questions (Parent/caregiver of young person with disability, 18-25 years)

Make it face to face - meet, speak, see the impact (Parent/caregiver of child with disability, nine years and under)

I have actually suggested to a Minister, that they have a COMPLEX CASE UNIT, consisting of Medically trained ppl, qualified therapists etc, so when a Complex Case, like my son's is submitted, that it goes straight to this team. I got told, No, when I asked to meet with this Minister, to discuss this (Parent/caregiver of young person with disability 18-25 years)

While NDIA have internal processes for referring participants to a Complex Support Needs Pathway, there is little public information on the NDIS website. This means that NDIS participants may not be aware of their eligibility for the pathway, leaving referral up to subjective assessments of NDIA planners. There is no transparency or accountability built into the process, nor any clear criteria for determining eligibility.³⁷

Ten per cent (13 responses) pointed to the need for **better training for NDIA staff**. This included trauma- and disability-informed empathetic and compassionate communication, as well as subject matter knowledge, with assessments made only by those with professional and/or lived experience of disability.

They need to read the reports given to them. No one person can be in a position to make a decision regarding somebody's disability access or needs. There are literally teams hired by participants that understand their needs and supports they require. These are the only professionals that should have an opinion and a say into supports provided. These are medically trained professionals which is a lot more qualified than any planner at NDIA (Parent/caregiver of child with disability, nine years and under)

Educate planners about discriminatory practices and abusive language towards parents and caregivers and participants themselves (Parent/caregiver of child with disability, 10-14 years)

Seven per cent (9 responses) advocated for **systems change**, reducing the burden on the family/individual with disability through more holistic and joined-up coordination between the NDIS, medical professionals, coordinators and assessors. There were also suggestions for continuity of care through one caseworker/coordinator.

Systems need to work together to address people's needs holistically. Separating services into disability/child development/health/mental health/education only creates gaps where the most vulnerable people have additional problems accessing services. The complexity of systems reduces cost for government by abandoning people with complex needs (Parent/caregiver of child with disability, 10-14 years)

Having one case worker work on it. Not swapped between different people (Parent/caregiver of child with disability, nine years and under)

25

³⁷ Limited public information about the Pathway is available through the Disability Royal Commission website and Freedom of Information requests. It was launched in 2018 "to provide specialised support for people with disability who experience personal and situational factors beyond the scope of the typical NDIS Pathway." Eligibility criteria does not appear to be intersectional or holistic, with target groups limited to behaviours of concern, young people in residential care, returning from care, in youth justice or out-of-home-care, and homelessness. See: DRC (2023) NDIA Practice Guide: Complex Support Needs Pathway, DRC (2023) NDIA Standard Operating Procedure: Referral for Complex Support Needs; NDIS (2023) FOI: Referral to the Complex Support Needs Branch.

Appendix A: Who took the survey?

Respondents who were parents and caregivers

Seventy-one per cent (197 responses) of respondents were parents and caregivers of children and young people with disability. Of these parents and caregivers:³⁸

- Ninety-two per cent cared for a child or young person who was an NDIS participant.
- The most common disability types in the children and young people they cared for were Autism (73 per cent), then ADHD (52 per cent), Intellectual Disability (36 per cent), and psychosocial disability or mental health condition (e.g., depression, anxiety) (34 per cent). Just over a fifth reported physical disability and learning disability (e.g., dyslexia), 18 per cent other sensory disability (i.e., other than blind/low vision or D/deaf or hard of hearing, which were listed separately), and 15 per cent other neurological disability (e.g., epilepsy, acquired brain injury, cerebral palsy). Three per cent were blind or low vision, and three per cent D/deaf or hard of hearing.
- A third cared for a child who was nine years old or under, 28 per cent for a child 10-14 years, 16 per cent for a child 15-17 years, and 21 per cent for a young person 18-25 years.
- Fifty-seven per cent of the children and young people they cared for were boys and men, 35 per cent were girls and women, and four per cent were non-binary.
- Nineteen per cent of children and young people cared for were from a non-metropolitan area (not a capital city), 11 per cent identified as culturally and linguistically diverse, seven per cent Aboriginal, and six per cent LGBTIQA+.

Respondents who were children and young people with disability

Nine per cent (25 responses) of respondents were young people with disability under the age of 25. Of these children and young people with disability who responded³⁹:

- Seventy-four per cent were NDIS participants or applicants.
- The most common disability types were physical disability (54 per cent), then Autism (50 per cent), psychosocial disability (50 per cent), and ADHD (46 per cent). A quarter of respondents reported Intellectual Disability. Seventeen per

³⁸ Out of a total of 190 responses (7 skipped the questions).

³⁹ Out of a total of 24 responses (1 skipped the questions).

- cent reported other neurological disability (e.g., epilepsy, acquired brain injury, cerebral palsy), and 12 per cent reported learning disability (e.g., dyslexia).
- Thirty-seven per cent of young respondents were women or girls, a third were men or boys, and a fifth were non-binary.
- Fifty per cent identified as LGBTIQA+, 29 per cent were from a nonmetropolitan area (not from a capital city), and a quarter were from a culturally and linguistically diverse background.

Respondents who received an eligibility reassessment letter

Fifty respondents (25 per cent) had received an eligibility reassessment letter, and shared about the experience and outcome as well as views on the process and how it could be improved.

Of respondents who received a letter,⁴⁰ 89 per cent were received by parents/caregivers of children and young people with disability. Sixty-one per cent of these were for children nine years and under, and 28 per cent for children aged 10-25. 76 per cent of the children and young people were Autistic, and 57 per cent ADHD. Eleven per cent were Aboriginal, 11 per cent were from a non-metropolitan area, two per cent identified as LGBTIQA+, and two per cent as culturally and linguistically diverse.

Eight per cent (four respondents) of letters were received directly by young people with disability, of which 75 per cent were Autistic, 75 per cent identified as LGBTIQA+, and 75 per cent as culturally and linguistically diverse.

Seventy-one per cent had received their letters in the past six months (41 per cent within the past 1-3 months and 30 per cent in the past 4-6 months). While 28 per cent had the extended 90 day period to provide additional evidence, 24 per cent only had 28 days to provide additional evidence. Two respondents said that they had less than 28 days to provide additional evidence. A further 28 per cent were unsure how long they had to provide additional evidence, indicating that the process is not clear or easy to understand.

Twenty-two per cent were removed from the NDIS following their reassessment. A further 26 per cent had their funding drastically cut or services removed. These figures were even higher for children nine years and under, with 32 per cent removed from the NDIS.

-

⁴⁰ Out of a total of 46 responses (4 skipped the question).

Appendix B: Social media summary

Background

Between 7 and 19 May 2025, CYDA ran a social media campaign promoting its survey on community experiences of NDIS eligibility reassessments. The campaign involved paid ads and organic posts (including one video) across Facebook, LinkedIn, Instagram, and TikTok.

As of 22 May, CYDA had received 107 comments across platforms, with many writing about their experiences. While some of these users may have gone on to also provide feedback through the survey, others may not have.

This summary outlines some common sentiments expressed but is not a detailed analysis.

It must be noted that:

- CYDA was not able to gather demographic information about commenters
- Unlike the survey, social media responses were not limited to people with lived experience with disability or of the reassessment process, but included members of the general public reached by ads
- Comments were often about the NDIS generally and not the eligibility reassessment process itself
- Some comments could be characterised as aggressive and/or ableist.

Notable observations

Overwhelming dissatisfaction with the eligibility reassessment process

Like in the survey, most commenters across platforms—especially those who said they were NDIS participants or applicants—described being unhappy, scared or stressed with the process.

One comment on Facebook, liked by four other users, read:

"I have eight comorbidities and chronic non malignant pain. And after God knows how many reports and assessments they determined that I'm not disabled enough to need support. Such a waste of my life."

Another comment on TikTok, hearted by two other users, read:

"The paperwork involved with these government organisations just adds extra stress onto already stressed people imo."

Another user wrote:

"Trying to get an asd assessment for my son atm. All the information I'm finding out about ndis is frightening and I currently can't get any help as adhd isn't enough."

A small number of positive experiences

None of the 222 respondents to the official survey selected the option 'positive' when asked to describe how they felt about the eligibility reassessment process. However, a small number of commenters on social media expressed positive sentiments about the NDIS

One comment on Facebook, liked by four other users, read:

"Nope, as soon as we got our diagnosis we had all the support we needed. Very surprised."

Another comment on TikTok, hearted by three other users, read:

"I gotta say I was dreading ndis because of all the horror stories id been told, they've been nothing short of fantastic for my son. It took around 2 months start to finish to get him sorted and they've been so helpful quiding me through everything."

A user responded to this with:

"I came to write this exact comment! I've actually had a fantastic experience..."

Concerns about rorting and fraud

A small number of commenters expressed concerns about the misuse of NDIS funding, primarily by providers.

One comment on Facebook, liked by 11 other users, read:

"NDIS is the biggest scam of the century"

Another, liked by two other users, read:

"Blessed are those in NDIS funding. But many providers are rorting the system."

A third, liked by 18 other users, read:

"So many criminals and half truths in this so called industry. Those that need it can't get it, those that know how to play the system get it."

Support for or reflection on the reasoning behind reassessments

Some users agreed with the need for eligibility reassessments, while others highlighted early intervention provisions as the reason behind increased reassessments for children under nine.

One comment on TikTok read:

"Good. Every second person is on ndis. If your child really does have a significant disability there won't be a problem"

Another comment, hearted by three other users, read:

"They are kids under 9 because the system changes around that age and early intervention support looks different and has a different criteria to other part of the NDIS."

Takeaway

Overwhelmingly, people with experience of the reassessment process shared similar sentiments to those expressed in the survey.

However, responses on social media were generally more mixed, with some people voicing positive sentiments about the NDIS, scepticism, and support for reassessments.

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

Twitter: @CydaAu Instagram: cydaaus

cyda.org.au

