

NDIS and Your Rights Webinar: Key Takeaways (24 September 2025)

Content note: this summary contains references to ableism, loss of supports, and trauma. It is based on the powerpoint slides from the webinar.

What was the webinar for?

An eligibility reassessment is a check to make sure National Disability Insurance Scheme (NDIS) participants still meet the requirements to receive NDIS funding. In late 2024, the National Disability Insurance Agency (NDIA) began conducting significant numbers of reassessments. Over 1200 reassessments are being conducted weekly, with 48% (600 participants a week), being removed from the NDIS. 80% receiving reassessment letters are children aged five to nine.

In CYDA's survey about eligibility reassessments in May 2025, we heard from our disability community that you feel worried, scared and confused about reassessments. We want to provide practical and proactive support, and the information you need to self-advocate about reassessments.

CYDA's Report on NDIS Eligibility Reassessments is available at this link: <u>CYDA's</u> NDIS Eligibility Reassessments 2025 Survey Report.

Who we heard from

The session was chaired by **CYDA's Board Chair Ebe Ganon** (she/they). We heard from four speakers from the disability community and legal sectors:

- Kerryann Stanley (she/her), Manager, First Peoples Disability Network
- Jenny Karavolos (she/her), Co-chair, Australian Autism Alliance
- Louis Bowden (he/him), Case Lawyer, Villamanta Disability Legal Service
 Inc
- Liam Thatcher (he/him), Advocacy and Policy Officer, Disability Advocacy
 Network Australia

What our survey found

Reassessments are targeting children nine and under, Autistic children, First nations children and those from diverse backgrounds

- CYDA's survey about NDIS eligibility reassessments received 222
 responses over 10 days. 71% were parents and caregivers, and 9% were
 young people with disability aged 25 or under. Most were NDIS participants or
 applicants. Common disabilities included Autism, ADHD, intellectual disability,
 psychosocial disability, physical disability, and others.
- 23% had received an eligibility reassessment letter, and 75% within the
 past six months. 76% who received letters were Autistic, 61% were parents of
 children aged nine or under, and 11% were Aboriginal. First Nations
 children and young people were nearly twice as likely to have received a
 reassessment letter (42% compared to 23% overall).
- Nearly half of respondents who were reassessed said they were removed from the NDIS or had funding reduced. Rates of removal and loss of funding were higher for children nine and under, Autistic children and young people, those from diverse backgrounds, and First Nations children.
- **Top issues** respondents reported were removal and loss of supports without clear reasons, severe emotional toll from the process, that the process is not fair or reasonable, or clear, and they received poor treatment by NDIA staff.
- Suggestions for improvements:
 - Clear, timely and accessible communication
 - Fair and more transparent assessment process
 - NDIA staff training and cultural change
 - Person-centred and individualised support
 - Broad systemic changes such as improving coordination, stopping reassessments, and continuity of support.

What can we do?

Uphold cultural rights: Kerryann Stanley, FPDN

- Disability in Aboriginal and Torres Strait Islander communities must be understood through a cultural lens. People with disability have the same rights as everyone else. For First Nations peoples with disability, this must include cultural rights. Cultural rights are not separate from other rights—they are foundational. This is supported by the UN Convention on the Rights of Persons with Disabilities, which Australia has ratified. The UN Convention on the Rights of Persons with Disabilities is available at this link: United Nations Convention of the Rights of Persons with Disabilities
- Cultural rights for First Nations children include connection to Country,
 participation in kinship and community, speaking and maintaining language,
 sharing and learning cultural knowledge. These are central to identity,
 healing, and social and emotional wellbeing. When children are
 disconnected from culture, it can create deep trauma, especially when they
 are already navigating the barriers of disability.
- Western, medical model of disability, which often doesn't reflect Indigenous ways of knowing, being and learning. Eligibility reassessments, especially when bureaucratic or rigid, can lead to the loss of essential supports if a child is deemed no longer eligible, cause confusion or disengagement when processes feel culturally unsafe, overwhelm families especially where there are language or literacy barriers, and sever important cultural ties if cultural support workers or therapists are removed. Families often lack culturally competent advocacy to challenge decisions, and children may be funnelled into mainstream services that don't reflect their needs or identity. This is a violation of cultural rights and fuels intergenerational trauma and systemic disadvantage.
- To uphold rights of First Nations children:
 - o Reassessments must be culturally safe, strengths-based, and flexible
 - o Embed First Nations worldviews in NDIS processes.
 - Families supported by First Nations-led organisations during reviews.

Cultural supports must be recognised as essential, not optional.

Tailored and nuanced support to Autistic children: Jenny Karavolos, Australian Autism Alliance

- Autism doesn't "fit neatly" into categories. Functional needs can be hidden or vary. Experiences of day-to-day life are dynamic based on individual experience of systemic, environmental, and interpersonal barriers.
- Autistic people's needs are complex and change over time. Using levels
 of functioning such as "low" or "high" is unhelpful. Supports need to be
 individualised and consider the whole person.
- Families are experiencing anxiety and burnout from reassessments.
 Those with less money, time or access to specialists struggle to produce evidence and with the extra costs for reports. There is greater inequity for rural, First Nations, and culturally and linguistically diverse families.
- We want to avoid loss of therapy and trained workers; skill regression, social isolation, change of routine, anxiety from disrupted supports; missed school or participation; impact on carers; and long-term developmental impact.
- We need to design the ecosystem to understand real-life impact:
 - Recognise autism as lifelong
 - Focus on needs, not diagnosis
 - Clearer communication and longer timeframes
 - No gaps guarantee with no child removed without alternatives in place
 - Co-design with Autistic people and families
 - Instate a National Human Rights Act
- Suggestions for how to prepare for being reassessed include keeping records,
 watching the timelines, challenging decisions if needed, using your right to
 communicate with the NDIA delegate, seeking advocacy support early, linking
 in with other supports and connecting (Disability Representative
 Organisations, Local Area Coordinators, peer supports, school, health and
 community services), and looking after yourself.

Understand reviews and appeals processes: Louis Bowden, Villamanta Disability Legal Services Inc.

- There are four stages to the reassessment process:
 - 1. NDIA reassessing your eligibility
 - 2. NDIA decision about your eligibility
 - 3. Your right to request a review of their decision, and
 - 4. Your right to appeal their decision.
- If you do receive a reassessment letter:
 - Contact NDIA to request more information and/or more time.
 - Notify your NDIS support team (if appropriate)
 - Note the timeframes make sure you don't incur a debt.
 - The NDIA call centre is useful for enquiries, but don't rely on them for taking notes of conversation – put things in writing.
 - Write a letter to NDIS to request further information:
 - 1. Why eligibility is being reassessed
 - 2. What additional information you need to provide
 - What targeted questions are needed for any relevant person or provider the NDIA wants more information from
 - 4. Confirmation of 90-day timeframe or request for extension of timeframe (if required)
- If you don't hear back from the NDIA, follow up. If no response, then you
 need to provide the updated information within the 90-day timeframe. If they
 decide to remove your NDIS funding, you normally have 28 days from
 decision date until you cannot use your funding anymore. If you have therapy
 funding you might be able to use it to get appropriate reports during this time.
- If you do not agree with the decision: request an Internal Review from the NDIA. You can do this by emailing enquiries@ndis.gov.au or calling 1800 800 110. An internal review request must be made within 90 days of receiving the decision in writing. If not done by then it is a deemed confirmation of the original decision under s 100(6A) of NDIS Act. When you make the request, ask for an urgent internal review. Also ask the NDIA to wait for the internal review outcome before removing you from the NDIS. Explain the risks to you

- if you don't have NDIS funding. The Internal Review should be looked at within 60 days, submit a complaint if it is outside this period.
- External Review: If the Internal Review decision is still to remove your NDIS
 access or you still do not have a decision, you can ask for an external review
 to the Administrative Review Tribunal (ART). You must apply to the ART
 within 28 days of receiving the internal review decision.
- Stay Application: Once you have made an application to the ART, you should let them know as soon as possible that you would like to have access to NDIS supports until there is a final decision from the tribunal process. This is called a 'stay' application (a form is available online through the ART's Request for stay order form). If a stay is granted, you'll receive guidance from ART about timelines for submission of additional evidence and steps for progress towards resolution or final hearing. Risk: If the stay application is unsuccessful, the NDIA may try to recover funds and you may incur debt.
- Alternative Dispute Resolution and the Case Conferencing process: This
 is a mediation process that occurs at the start of the ART review. They will
 likely ask for further evidence to ensure success, such as a Functional
 Capacity Assessment, and targeted questions to Applicant's medical
 practitioners. You will also receive documents, and if not included, ask for
 the Technical Advice and Practice Improvement Branch advice.

What's next for NDIS?: Liam Thatcher (he/him), Disability Advocacy Network Australia

- NDIA have claimed that increased reassessments are due to COVID backlog. There is a 90 per cent removal rate for children, 10 per cent for adults. Many 90-day periods to provide information are coming to an end now.
- The overall proportion of people going to the Administrative Review Tribunal (ART) remains relatively small compared to those receiving letters. This could be because people are only just learning their rights, the window is too short to respond, and the NDIA takes too long to process reviews.

- In the future, there may be procedural fairness issues that require the NDIS
 to only send letters where eligibility is actually in doubt. More clarity is needed
 on how they select people to send letters to and make decisions.
- The unfair process pushes more people to the review system which can be long, tough and time-consuming. Responses and timeframes for internal reviews can vary a lot, but the last NDIS Quarterly Report said that 75% of internal reviews are processed within 60 days.
- The Thriving Kids announcement by NDIS Minister Butler in late August will re-draw a lot of boundaries. This will be a form of targeted Foundational Supports for children 0-8 years, aimed to reduce growth of NDIS. It will shift some disability assistance to general available services at the State/Territory level, not through an NDIS plan. Federal Governments will commit \$2 billion, with State and Territory government amounts not yet agreed.
- Thriving Kids has flagged changes to access for children based on age, level of impairment, impairment or disability type. There have been deeply troubling remarks about autism, evidence, permanence and costs. There has been a promise to 'grandfather' people already part of the NDIS.
- There is a potential opportunity for tailored supports through Thriving Kids
 if it is done right with co-design and enough time for implementation. You
 can submit your views to the Parliamentary Inquiry into the Thriving
 Kids Initiative by 10 October online at this link: Thriving Kids Inquiry.
- In the short term, people will still be subject to eligibility reassessments.
 Ensuring that people can find the services they need in either system is going to be very important.

Further information

For First Nations children and families

- National Agreement on Closing the Gap at this link: <u>National Agreement on</u>
 Closing the Gap Priority Reform 3
- First Peoples Disability Network (FPDN) Reports at this link: <u>First Peoples</u>
 <u>Disability Network Our Work</u>

For Autistic children and families

- Autism CRC Knowledge Centre at these links: <u>National Framework for</u>
 <u>Strengths and Supports</u>, <u>National Guideline for the Assessment and</u>
 <u>Diagnosis of Autism in Australia</u> and <u>National Guideline for Supporting Autistic</u>
 Children in Australia
- Amaze Inclusive education at this link: <u>Championing Inclusion in the</u>
 Classroom
- Australian Autism Alliance at this link: <u>Australian Autism Alliance</u>

About Review and Appeals Processes

- To request an Internal Review by the NDIS, you can email enquiries@ndis.gov.au or call 1800 800 110.
- The Administrative Review Tribunal Stay Application form at this link: <u>Stay</u>
 <u>Application Form</u>
- Link to relevant ART case at this link: ART Review case
- Contact details for Villamanta Disability Rights Legal Service Inc. PO Box 7328 Geelong West VIC 3218. Advice Line: 1800 014 111 Mon-Fri: 10-4 p.m. Admin Line: 03 5260 1845, Website: www.villamanta.org.au, TTY Users: phone 133 677 then ask for 03 5260 1845.

Policy information

- NDIS Quarterly Reports at this link: NDIS Quarterly Reports
- Minister Butler's Thriving Kids announcement at this link: Press Club Speech

External Supports

We acknowledge that some of the content in the webinar may have been challenging or confronting. If you need support, you can contact:

- Lifeline call 13 11 14 or text 0477 13 11 14
- Beyond Blue call 1300 224 636
- Yarning SafeNStrong (First Nations) call 1800 95 95 63
- Rainbow Door (LGBTQIA+) call 1800 729 367
- QLife (LGBTQIA+) call 1800 184 527
- Kids Helpline call 1800 551 800

Note: Lifeline, Beyond Blue, Kids Helpline, and QLife all have webchat options. Lifeline also offers a 24-hour text line.

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 **LinkedIn:** au.linkedin.com/company/cydaau

Instagram: cydaaus

cyda.org.au

