
Response on NDIS Access Changes Consultation

Submitted on behalf of Neurological Alliance Australia by Rohan Greenland (Chair) and Anne Wilson (Deputy Chair)

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Executive Summary

Neurological Alliance Australia (NAA) welcomes the opportunity to respond to the Department of Health, Disability and Ageing consultation on NDIS access changes. NAA welcomes the proposed focus on human rights, and fair, evidence-based NDIS access decisions.

NAA supports the proposal of moving beyond diagnosis-based access lists to an assessment of functional capacity, provided the approach is validated for progressive, episodic, fluctuating, energy-limiting and less visible impairments. Clinical history and lived experience must inform how assessment results are interpreted. Known conditions may provide strong evidence of whether an impairment is likely to be lifelong and how function may change.

Applicants should not have to reach a point of crisis, repeat evidence that the NDIA already holds or wait for a definitive rare-disease diagnosis when permanent impairment and substantial functional impact can otherwise be established. Evidence requirements should be proportionate, with timely decisions, clear reasons and accessible review pathways.

NAA's inaugural Neuro Survey 2026 received 3,805 responses. Among respondents living with a neurological condition:

- 29.3% of 2,620 reported waiting more than four years for a diagnosis
- 51.1% of 2,543 found neurological medical care difficult to access
- 47.5% of 1,988 delayed or skipped care, support or treatment because of cost
- 22.2% of 2850 reported receiving NDIS funding.

Free-text responses from 92 respondents emphasised the need for more coordinated and accessible models of care, including responsive NDIS supports, timely specialist access, and practical supports such as respite and transport. Although not representative of NDIS applicants, its findings illustrate the barriers that repeated or costly specialist evidence can create.

NAA's *Blueprint for a National Action Plan for Neurological Conditions* calls for early intervention, equitable support and coordination across health, disability and aged care.¹ The access process must be linked to those broader systems. A referral elsewhere is meaningful only when the person can really access a suitable service. Where a person aged under 65 years is ineligible for the NDIS, the NDIA should explain the decision, preserve review pathways and assist with a supported connection to suitable services that are available.

NAA and members of the NDIA's Neurodegenerative, Palliative Care and Rare Diseases Advisory Group raised detailed concerns about functional assessment and permanence in our May 2026 submission to the Senate Community Affairs Legislation Committee on the NDIS Amendment Bill.² It is noted that since then, the Department has published further explanations of the enacted treatment safeguards.³

This submission focuses on how the access process and future guidance should give those safeguards practical effect.

About Neurological Alliance Australia

Neurological Alliance Australia is a national alliance of 50 not-for-profit organisations (see membership on p 8) representing the needs of over 4.5 million Australians living with neurological and neuromuscular conditions⁴. NAA advocates on shared priorities to improve quality of life for people living with these conditions, strengthen access to care and support, and increase investment in neurological research treatment and care.

Recommendations

NAA makes four recommendations being:

Recommendation 1

The draft guiding principles be strengthened and supported by practical guidance

- Explain how NDIA staff will apply the principles, with training and a disability-aware workforce that includes people with disability in decision-making roles.
- Clarify Principle 1 by explaining how the amended NDIS Act will be applied consistently with the human rights of people with disability.
- Clarify Principle 3 so that consistent methods still produce individual decisions. People with the same condition can have very different functional impacts and trajectories.
- Expand Principle 5 to recognise progressive, degenerative, fluctuating, episodic, rare and less visible impairments, timely early intervention where eligibility requirements are met, and gaps affecting older people with disability.

¹ https://neurologicalalliance.org.au/wp-content/uploads/Blueprint-for-National-Action-Plan-25-Aug-2025_FINAL.pdf

² <https://neurologicalalliance.org.au/wp-content/uploads/Submission-to-Senate-Community-Affairs-Legislation-Committee-on-NDIS-Amendment-Bill-2026.pdf>

³ <https://www.health.gov.au/our-work/ndis-legislation-changes/amendments/ndis-amendment-securing-the-ndis-for-future-generations-bill-2026/about-the-changes-to-the-ndis>

⁴ <https://www.aihw.gov.au/reports/neurological-conditions/neurological-conditions/contents/summary>

- Expand Principle 6 to require timely responses, clear reasons for decisions and accessible review information.

Recommendation 2

The NDIS access process be fair, disability-informed and centred on lived experience

- Assess the functional impact of impairment over time, drawing on clinical evidence and the accounts of applicants, families and carers, rather than relying on diagnosis or a single assessment.
- Communicate clearly and offer flexible ways to participate, including adjustments for cognitive, communication and fatigue-related needs. Resolve missing information or disputes through direct discussion where possible.
- Provide accessible referral pathways, use existing evidence, streamline assessment for clearly eligible applicants and train NDIA staff to understand the diversity of neurological and neuromuscular conditions.

Recommendation 3

Permanence and treatment requirements reflect individual clinical circumstances

- Consider reports from relevant health professionals alongside information from people with lived experience and their families and carers. Evidence should address functional impact, likely progression and the benefits and limits of available treatment.
- Train decision-makers to interpret this evidence, seek specialist advice where needed and explain any decision that differs from relevant clinical evidence.
- Use current peer-reviewed and other relevant clinical evidence, informed by relevant disability representative organisations, particularly where evidence for rare conditions is limited. Ongoing symptom management or treatment-dependent stability should not, by itself, be taken to mean that an impairment is temporary.

Recommendation 4

Co-design and test implementation

- Consult with NAA members, disability representative organisations, clinicians and people with lived experience on specific tools and thresholds. Publish equity and accuracy testing, reassessment safeguards and impact monitoring before commencement.

Responses to the consultation questions

Guiding principles

- *Do the draft guiding principles provide the right foundation for a future NDIS access process?*
- *Should any principles be added, removed or changed?*

NAA supports principles grounded in human rights, lived experience, equity, transparency and person-centred decision making. The principles need clearer direction on how they will work in practice.

The NDIA should publish guidance, train staff and assessors to apply it, and check whether decisions reflect it. A disability-aware workforce should include people with disability in senior decision-making roles and support staff to disclose disability safely.

Principle 1: Aligned to the NDIS Act and the human rights of people with disability. NAA has raised concerns about the effect of recent legislative changes on people with progressive, episodic and rare conditions.⁵ The final principle should explain how rights, autonomy and procedural fairness will be protected when the new access requirements are applied. Applicants need accessible reasons for decisions and effective review pathways.

Principle 3: Evidence-based and consistent. Consistency should mean using a fair and reliable process, with similar evidence assessed to the same standard. It should not mean treating everyone with the same diagnosis alike. Neurological and neuromuscular conditions can vary substantially between people and over time. Assessments should consider usual function, better and worse periods, recovery time, support dependence and likely progression. A standardised result should be interpreted alongside clinical history and lived experience.

Principle 5: Equitable, inclusive and safe. The wording should expressly recognise disabilities that are degenerative, complex, fluctuating, episodic, energy-limiting or not immediately visible. People who meet the early intervention requirements should be able to enter before avoidable decline, with timely processes for rapidly progressive conditions. The principle should also address gaps at the boundary of the NDIS and aged care. In particular, NAA supports consideration of the NDIS Review's proposed legislative change allowing existing participants, when they turn 65 years of age, to receive appropriate NDIS and aged care supports concurrently, without duplication.

Principle 6: Transparent, proportionate and accessible. Add a commitment to timely responses. Applicants should know what evidence is needed, when to expect a decision, why evidence was accepted or disregarded, and how to seek a review.

NAA recommends that the draft guiding principles be updated to:

- explain how they will be implemented, including staff training, quality assurance and a more disability-aware NDIA workforce
- clarify under Principle 1 how rights and procedural safeguards will be upheld when applying the amended Act
- clarify under Principle 3 that a consistent method must still produce decisions based on each person's impairment and circumstances
- recognise under Principle 5 progressive and variable conditions, timely early intervention and the needs of older people with disability
- include timely communication and transparent decisions under Principle 6.

⁵ <https://neurologicalalliance.org.au/wp-content/uploads/Submission-to-Senate-Community-Affairs-Legislation-Committee-on-NDIS-Amendment-Bill-2026.pdf>

Design of access decision-making process

- *What does the Department need to consider when designing an access decision-making process that is fair, consistent, transparent, disability-informed and evidence-based?*
- *How could the access decision-making process, including referral pathways, be designed to reduce administrative burden and make it easier and more equitable for people with disability, their families and carers to understand what information is needed and how decisions are made?*
- *How could this support a proportionate approach to minimise the assessment burden on persons who are clearly eligible with very significant functional impairment?*
- *What should be considered to ensure the access decision-making process, as well as referral pathways, works well for all disability cohorts including people with communication, cultural, cognitive, degenerative, fluctuating, episodic or complex support needs?*

NAA asks the Department to consider the following in designing the process:

- **Fair and disability-informed decision making:** Assess real-world function over time, rather than relying on diagnosis alone or functional performance at one appointment. Test assessment tools and thresholds with people across neurological and neuromuscular conditions before use.
- **Lived experience and individual need:** The NDIA should embed lived experience into the design and operation of the access process by involving people with disability, their families and carers in decision making and understanding. It is critical that people are given a meaningful opportunity to describe how their impairment affects daily life. Provide flexible appointments, rest breaks and communication methods for people affected by fatigue, cognition, pain, speech or other communication difficulties. Clinical evidence about a condition's likely course should inform each decision, alongside the person's individual circumstances and support needs.
- **Clear and accessible pathways:** The NDIA should provide simple, consistent and accessible self-referral pathway and assisted-referral pathway options. Offer a streamlined pathway where existing evidence clearly establishes a permanent impairment and significant functional impact, and an expedited process where documented decline is likely to make delay harmful. Where a person does not meet NDIS access requirements, clearly explain the decision and offer a supported connection to a suitable service that is available.
- **Improved communication:** Provide a plain-language evidence guide, a contact point and clear timeframes. Before refusing access because information is missing, contact the applicant to identify the specific gap. Written decisions should address material clinical and lived-experience evidence, explain any contrary finding and set out review options.
- **Reducing burden and improving equity:** Reuse reports and NDIA records, with consent, instead of repeatedly asking people to prove an established impairment.

Request a new assessment only where it will resolve a material question, and assist with costs and practical barriers. In NAA's Neuro Survey 2026, 29.3% of 2,620 diagnosed respondents living with a neurological condition reported waiting more than four years for diagnosis, while 47.5% of 1,988 respondents reported delaying or skipping care, support or treatment because of cost. The survey is not a representative study of NDIS applicants, but it illustrates why repeated specialist-evidence requirements could disadvantage some people.

- **Using evidence appropriately:** Consider standardised assessments alongside relevant medical specialist, allied health and nursing reports, longitudinal records and the person's and carer's stories. Assessors should explain how they weighed any conflicting evidence. A lack of a definitive diagnosis should not prevent consideration of a well-evidenced permanent impairment, particularly for rare conditions.
- **NDIA workforce capability:** Training the NDIA workforce is crucial to implementing any new changes to the NDIS. Decision-makers should be trained in progressive, fluctuating, episodic, cognitive and less visible impairments, and give them access to specialist advice. Training should cover evidence interpretation, accessible communication, cultural safety and how to resolve an access dispute through direct discussion where possible.

NAA recommends that the NDIS access process:

- be fair, disability-informed and centred on lived experience, with decisions based on functional impact over time rather than diagnosis alone or a single assessment
- provide clear communication, flexible engagement with applicants and their chosen supporters, accessible reasons and a practical approach to resolving disputes
- use existing evidence, proportionate pathways for clearly eligible applicants, supported referrals to available services and a workforce trained in complex and variable disabilities.

Evidence requirements

- *What factors and evidence should be considered when determining whether an impairment is permanent or likely permanent, including whether appropriate treatment is likely to improve the functional impact of an impairment?*

Decisions about permanence and treatment should draw on qualified health-professional evidence and the experience of the person living with disability. Families and carers can contribute. NDIA staff need training to interpret these sources together and to explain why they depart from relevant treating evidence.

The evidence requirements should consider:

- **Reports from relevant medical specialists:** These may describe a diagnosis or a likely diagnosis, the impairment's duration and likely course, and whether it is fluctuating, episodic, progressive and/or degenerative. They should address treatment options that are clinically appropriate for the individual, likely benefits

and risks. A definitive rare disease diagnosis should not be essential where permanence and functional impact can otherwise be established.

- **Reports from other relevant health professionals including allied health professionals and nurses:** These can describe usual function and whether NDIS support needs are likely to improve, maintain and/or reduce disability progression in respect of mobility, cognition, communication, self-care, participation, work or study.
- **Information provided by people living with disability and their families and carers:** This should describe day-to-day variation, treatment effects, the consequences of attempting activities, and the assistance needed to complete them. It should also allow the person to explain why an option has not been undertaken, including clinical suitability, side effects, cost, availability and effects on quality of life.
- **Peer-reviewed, relevant and timely research:** Research can inform the likely course of an impairment and the expected effect of treatment. Assessors and planners should be trained to appropriately interpret this research or refer to specialist NDIA staff or other appropriately qualified clinical advice when interpreting it. Disability Representative Organisations, including NAA members, can help identify reliable evidence and gaps in knowledge, particularly for rare conditions.

The Department's guidance says that "appropriate treatment" does not require every possible treatment, must account for individual suitability and likely benefit, and is limited to publicly funded treatment.⁶ The access rules and staff guidance should show how these safeguards apply to neurological and neuromuscular conditions.

NAA recommends that new permanence and treatment requirements be driven by:

- evidence-based reports from relevant health professionals together with input of people living with disability, their families and carers
- comprehensive training for NDIA staff on interpreting and giving proper consideration to that evidence
- current, relevant peer-reviewed research reviewed by appropriately trained staff, with input from Disability Representative Organisations and other organisations on condition-specific evidence and gaps.

For more information about this submission and the work of Neurological Alliance Australia please contact:

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⁶ https://www.health.gov.au/our-work/ndis-legislation-changes/amendments/ndis-amendment-securing-the-ndis-for-future-generations-bill-2026/about-the-changes-to-the-ndis?utm_source=chatgpt.com

Current Organisational Members

- Australian NPC Disease Foundation (ANPDF)
- Brain Foundation
- Brain Injury Australia
- Cerebellar Ataxia Australia
- Childhood Dementia Initiative
- Cure CASK
- Dementia Australia
- Dystonia Network of Australia
- Emerge Australia (ME/CFS)
- Epilepsy Action Australia
- Epilepsy Australia
- Epilepsy Foundation
- FARA Australia
- FAST Australia (Angelman Syndrome)
- Fight Parkinson's
- FND Hope
- FSHD Global Research Foundation
- Fragile X Association of Australia
- Genetics Alliance Australia
- Huntington's Australia
- Homer Pack
- Klim Foundation
- Leukodystrophy Australia
- Meningitis Centre Australia
- Migraine Australia
- Mito Foundation
- Machado-Joseph Disease (MJD) Foundation
- Motor Neurone Disease Australia
- Multiple Sclerosis Australia
- Muscular Dystrophy Australia
- Muscular Dystrophy Foundation Australia
- Myasthenia Alliance Australia
- Myositis Association Australia
- Nerve Connection Foundation
- Neurological Alliance Queensland
- Neurological Council of WA
- Neuromuscular WA
- Palliative Care Australia
- Parkinson's Australia
- Polio Australia
- Post Polio Victoria
- Save Our Sons Duchenne Foundation
- SCN2A Australia
- Spinal Cord Injuries Australia
- Spinal CSF Leak Australia
- Spinal Muscular Atrophy Australia
- Stroke Foundation
- The Australian Young Onset Dementia Special Interest Group
- Tuberous Sclerosis Australia
- Young People in Nursing Homes National Alliance

Current Individual Members – individual researchers from:

- Macquarie University, NSW
- Murdoch Children's Research Institute, VIC
- Neuroscience Research Australia and University of NSW
- Perron Institute for Neurological and Translational Science, WA
- University of Sydney, NSW