



NDIS Access Changes Consultation

October 2026



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What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Three times as many women have MS than men. Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

George Pampacos
President

Rohan Greenland
Chief Executive Officer

NDIS Access Changes Consultation

Executive Summary

MS Australia welcomes the opportunity to respond to the Department of Health, Disability and Ageing on the National Disability Insurance Scheme (NDIS) access changes. This submission supports a fair, transparent and disability-informed access process that is centred on lived experience and recognises the real-world functional impact of disability over time. Access decisions must consider individual circumstances, fluctuating and degenerative conditions, and evidence from health professionals, people with disability, families and carers. MS Australia recommends clearer guiding principles, accessible referral pathways, streamlined processes for clearly eligible participants, reduced administrative burden, and comprehensive training for NDIA staff to ensure decisions are consistent, person-centred and evidence-based.

Lived Experience

This submission draws on the experiences and expertise of MS Australia's [Lived Experience Expert Panel](#) (LEEP) and state and territory [Member Organisations](#). LEEP members are people who live with MS or care for someone with MS and provide expert advice to inform MS Australia's advocacy. Our Member Organisations are registered NDIS providers delivering supports including support coordination, plan management, allied health, accommodation, respite, social support and in-home care. Some also support people with other neurological conditions, including stroke, Parkinson's disease, Huntington's disease, acquired brain injury and motor neurone disease.

MS Australia Recommendations

- The **draft guiding principles** be updated as follows:
 - Include more detail on how the principles will work in practice including how National Insurance Disability Agency (NDIA) staff will be trained to adapt to and implement them and how the NDIA will ensure a more disability aware workforce.
 - Update **Principle 1: Aligned to the NDIS Act and the human rights of people with disability** to include more detail on how the NDIA will address the disparity between human rights for people with disability and the changes to the NDIS Act.
 - Update **Principle 3: Evidence-based and consistent** to provide clear direction that an emphasis on consistency across the principles does not result in all people with the same condition being treated exactly the same and instead a focus on meeting the individual needs of each person applying to access the NDIS and their individual condition.
 - Update **Principle 5: Equitable, inclusive and safe** to recognise the degenerative nature of the conditions referenced and provide more equitable access including early entry and support for older people with disability.
 - Update **Principle 6: Transparent, proportionate and accessible** to include reference to timely responses to applicants.
- The **NDIS access process** be updated to:
 - be fair, disability-informed and centred on lived experience, with decisions based on the real-world functional impact of disability over time rather than diagnosis alone or a single assessment;
 - be centred in lived experience and include clear and improved communication, a more open approach to dealing with access disputes and flexible approaches to engaging with people with disability, their carers, families and nominees; and

- include clear and accessible referral pathways, appropriate use of existing evidence, streamlined pathways for people who are clearly eligible, and a trained NDIA workforce that understands complex, fluctuating and degenerative disabilities.

- New **permeance and treatment** requirements by should be driven by:
 - evidence-based reports from health professionals and the input of people living with disability, their families and carers;
 - comprehensive training for NDIA staff on interpreting and giving appropriate consideration to reports from health professionals and information provided by people with disability, their families and carers; and
 - peer reviewed, relevant and timely research that has been reviewed by appropriately trained staff and recommended by the relevant Disability Representative Organisations.

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?*

MS Australia supports the introduction of guiding principles that are focused on human rights, lived experience, equality, transparency and a person-centred approach. However, MS Australia does have some concerns with the principles as they currently stand. The principles are positive in theory but there is no detail on how they will work in practice.

The way that the NDIS currently operates does not align with the majority of these principles. Most decisions relating to NDIS access, assessment, planning and supports are not evidence-based but driven by cost and do not take into consideration lived experience. There is no person-centred approach and there is very limited transparency around decision making. NDIA assessors, planners and decision makers would need comprehensive training in these principles to ensure that they understand them and how to apply them. Further, the best way to ensure that these principles are embedded in the NDIS is to have a disability aware workforce with an emphasis on the employment of people with disability, including in senior decision-making roles. The NDIA also needs to create an environment where staff with disability feel safe to disclose their disability and their input is valued by the NDIA.

Principle 1: Aligned to the NDIS Act and the human rights of people with disability says that the access decision-making process will be aligned to both the NDIS Act and the human rights of people with disability. However, for many people living with disability the recent changes to the NDIS Act do not align with human rights.

‘Principle 1 needs to identify which is the higher priority - the NDIS Act or the human rights of people with a disability - we know from the recent NDIS legislation changes that the new legislation directly impinges on many of the human rights of people with a disability so there is no way to hit both targets within this guideline, one needs to have priority over the other’.

- **LEEP Member Rachel**

In our submission on the [NDIS Amendment Bill](#) MS Australia outlined our concerns regarding the changes to the NDIS Act and how they do not align with Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD)¹, including an emphasis on funding linked to financial sustainability over individual need and limited consultation of the reforms. We believe that the changes made to the Act do not meet the Articles under the CRPD relating to accessibility, living independently, personal mobility, health, habilitation & rehabilitation, work & employment and cultural life, recreation, leisure & sport.

Principle 3: Evidence-based and consistent has a strong emphasis on a consistent approach and application across disability cohorts. While it is important to have consistency across the scheme, MS Australia is concerned that this emphasis may lead to all people with a condition being treated exactly the same. MS is a complex neurological condition that is unpredictable, progressive and different for every person. Symptoms can fluctuate from day to day, needs can shift suddenly, and the condition can change significantly over a lifetime. For this reason, each person with MS must be assessed based on their individual need and the impact of the condition on them. The principles need to recognise that for the majority of people with disability, their disability is not consistent over time.

We recommend updating **Principle 5: Equitable, inclusive and safe** to recognise the degenerative nature of the conditions and provide more equitable access including early entry and support for older people with disability as follows:

- Change the current proposed wording to 'It should embed cultural safety, psychological safety and trauma-informed practice, and work effectively for people whose disability may be degenerative, complex, fluctuating, episodic or not immediately visible.'
- Providing early entry pathways for people with degenerative conditions so they have access to the NDIS early in their disease trajectory and can access support as their needs increase.
- Providing equitable access for older people with disability by allowing participants to receive supports in both the NDIS and aged care system concurrently as per the recommendation of the NDIS Review Final Report².

Ensuring that the NDIA responds to applicants in a timely manner is crucial to the effective operation of the Scheme. We recommend updating **Principle 6: Transparent, proportionate and accessible** to include reference to timely responses to applicants.

MS Australia recommends that the draft guiding principles be updated as follows:

- Include more detail on how the principles will work in practice including how NDIA staff will be trained to adapt to and implement them and how the NDIA will ensure a more disability aware workforce.
- Update **Principle 1: Aligned to the NDIS Act and the human rights of people with disability** to include more detail on how the NDIA will address the disparity between human rights for people with disability and the changes to the NDIS Act.
- Update **Principle 3: Evidence-based and consistent** to provide clear direction that an emphasis on consistency across the principles does not result in all people with the same condition being treated exactly the same and instead a focus on meeting the individual needs of each person applying to access the NDIS and their individual condition.
- Update **Principle 5: Equitable, inclusive and safe** to recognise the degenerative nature of the conditions referenced and provide more equitable access including early entry and support for older people with disability.
- Update **Principle 6: Transparent, proportionate and accessible** to include reference to timely responses to applicants.

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?*

Below are the recommendations for consideration when designing a new access decision-making process:

- **Fair and disability-informed decision making:** NDIS access decisions should avoid assessing people only on their 'best day' or diagnosis alone and instead focus on the real-world functional impact of disability over time. The NDIA should also be aware of how broader issues impact people with disability including health, social and community barriers.

'Assessments should not capture someone's ability only on their best day or during a short appointment. They need to consider fatigue, pain, cognition, mobility, mental load, recovery time, variability and the cumulative impact of disability. A fair process should look beyond diagnosis and consider the real-world impact of disability on a person's daily life, independence, participation and ability to function over time'.

– **LEEP member Deize**

- **Lived experience and individual need:** the NDIA should embed lived experience into the design and operation of the NDIS access process by involving people with disability, their families and carers in decision making and understanding. As outlined in our response above on the draft principles, decisions should always be individualised and reflect each person's circumstances and support needs. The access process should allow for a range of communication methods and flexible appointments that allow for cognitive and fatigue issues. They should also recognise the role of carers, families and nominees in supporting people with disability.
- **Clear and accessible pathways:** the NDIA should provide simple, consistent and accessible referral pathways that don't require people to navigate multiple systems or agencies and multiple referral options including self-referral and referrals from health professionals. The NDIA should also consider creating streamlined and specialist pathways for people who are clearly eligible, have significant functional impairment and/or live with degenerative or complex conditions.

'This could create streamlined pathways for people who are very clearly living with a disability. Ideally people living with significant and obvious disability aren't forced through unnecessary assessments'. – **LEEP member Julie**

- **Improved communication:** all communication with people with disability should be clear and easily understood. This should include plain language information on what evidence is needed, how decisions are made and clear timelines. NDIS assessors and decision makers should be adaptable to the language used by applicants. If applicants are not granted access to the Scheme, the basis for the rejection should be clearly outlined.

'Language and intellectual capacity should not have a negative impact. I have worked in the past with families who did not use the 'correct language' or terminology which has resulted in declined access or the need for documentation to be re-written'.

- **LEEP member Hannah**

- **Reducing burden and improving equity:** the new process should seek to reduce red tape, duplication, delays and unnecessary reassessments, while addressing barriers such as rural and remote locations, socioeconomic disadvantage, communication needs, cognitive impairment and the cost or wait times for medical reports. This includes a more open approach to solving access disputes including mediation-style options and making decision makers more accessible, especially when issues could be resolved with a quick conversation.
- **Using evidence appropriately:** the NDIA should use existing evidence wherever possible and give appropriate weight to reports from medical specialists, allied health professionals and people with disability and their families and carers. For more details on this see our response below on evidence requirements.
- **NDIA workforce capability:** as outlined throughout this submission, training the NDIA workforce is crucial to implementing any new changes to the NDIS. Staff must be appropriately trained, accessible and able to communicate openly with participants and nominees. Decision makers should understand fluctuating, degenerative, invisible and complex disabilities.

MS Australia recommends that the NDIS access process be updated to:

- be fair, disability-informed and centred on lived experience, with decisions based on the real-world functional impact of disability over time rather than diagnosis alone or a single assessment;
- be centred in lived experience and include clear and improved communication, a more open approach to dealing with NDIS access disputes and flexible approaches to engaging with people with disability, their carers, families and nominees; and
- include clear and accessible referral pathways, appropriate use of existing evidence, streamlined pathways for people who are clearly eligible, and a trained NDIA workforce that understands complex, fluctuating and degenerative 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?*

LEEP members support NDIS processes that are driven by reports from qualified and experienced health professionals and information provided by people with disability, their families and carers:

'Medical diagnosis and prognosis, including whether the condition is lifelong, progressive, degenerative or expect to persist despite treatment. Functional impact - consider mobility, cognition, communication, self-care, social participation and ability to work or study. Fluctuating and episodic conditions - recognise that a person may have significant impairment even when symptoms temporarily improve. Evidence from treating professionals - specialists, allied health and clinicians familiar with the person's condition'.

- **LEEP member Deize**

'A clinical diagnosis of a disability which is going to be lifelong and irreversible. There is no curative treatment and there are demonstrated negative functional impacts from the disability'.

- **LEEP member Julie**

'Diagnosis should definitely count for something in terms of permanency. But my biggest issue is determining 'appropriate treatment' - appropriate to who? the funding body or the individual living with a disability? Factors and evidence should include information from allied health professionals ...but most importantly statements from the participants/families/carers etc. I feel like too much funding is wasted on reports to prove something to the NDIA instead of on actual therapy that could reduce/improve the functional impact of an impairment. The information also needs to include the impact of treatment on quality of life and not just the face value of where someone is at in 'improving' their impairment'. - **LEEP member Hannah**

'Decisions need to be driven by medical personnel only - an admin specialist at the NDIA is unlikely to have completed the many years of study required to qualify them to make such determinations. Thus, a doctor needs to certify that a condition is permanent and any potential treatments. Once the doctor has stated this, the NDIA shouldn't be able to overrule or ignore any medical part of their statement'. – **LEEP member Rachel**

'Specialist doctors, GPs and other health professionals receive years of education about how to diagnose a disability and how to treat it so their opinions should be listened to and acted upon'. - **LEEP Member Anne**

Currently NDIS staff do not give appropriate weight to reports from health professionals and often make decisions that directly contradict them. They also do not listen to people with disability, families and carers on how an individual is impacted by their disability. Staff need better understanding of how to interpret reports from health professional and to balance the evidence they are provided with.

We believe that the permanence and treatment requirements under the new NDIS access and eligibility rules should consider the following:

- Reports from qualified and relevant medical specialists that include:
 - confirmation of the individual's diagnosis;
 - confirmation the condition is lifelong and irreversible;
 - whether the condition is fluctuating, episodic, progressive and/or degenerative;
 - treatments options for the condition and the impact of these treatments on the individual including on disability progression and quality of life; and
 - the current treatments being undertaken by the individual
- Reports from other relevant health professionals including allied health professionals and nurses regarding the individual's functional capacity and whether NDIS supports are likely to improve, maintain and/or reduce disability progression. This includes mobility, cognition, communication, self-care, social participation and ability to work or study.
- Information provided by people living with disability and their families and carers including:
 - what treatments the individual is currently accessing and the impact on their life and disability;
 - any treatments they haven't undertaken and reasons for this including quality of life, access, cost; and
 - the impact that accessing NDIS supports will have on their disability progression.
- Peer reviewed, relevant and timely research. Assessors and planners must be trained to appropriately interpret this research or refer to specialist NDIA staff. Disability Representative Organisations are a reliable resource for trusted research.

MS Australia recommends that new NDIS permeance and treatment requirements by should be driven by:

- Evidence-based reports from health professionals and the input of people living with disability, their families and carers;
- Comprehensive training for NDIA staff on interpreting and giving appropriate consideration to reports from health professionals and information provided by people with disability, their families and carers; and
- Peer reviewed, relevant and timely research that has been reviewed by appropriately trained staff and recommended by the relevant Disability Representative Organisations.

Reference

¹ United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Treaty Series, vol. 2515, 3.

² Department of the Prime Minister and Cabinet (October 2023). *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report*. Retrieved from: <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>



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