Lvl 4, Woden Centre
20 Bradley Street
Philip ACT 2606

mndaustralia.org.au

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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House Canberra ACT 2600

via email: Community.Affairs.Sen@aph.gov.au

RE: National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026

Thank you for the invitation to make a submission to the NDIS Amendment Bill (Securing the NDIS for Future Generations). Motor Neurone Disease Australia (MNDA) welcomes the opportunity to provide this submission on behalf of its members, the State MND Associations, and people living with MND.

What is MND?

MND Australia is the national peak body for state organisations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected.

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate the voluntary muscles, they become progressively weaker to the point that the ability to walk, speak, swallow and ultimately breathe is lost. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time.

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half within two years of diagnosis. There are no known causes for MND, apart from the up to 15% per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability, regardless of the age at onset, and a consequent need for a wide range of changing supports based on the person's complex needs. In 2025 there were an estimated 2,752 people with MND in Australia, with 1,018 registered NDIS participants receiving an average package size of $302,000.[1]

MND is a complex and rapidly degenerative disease requiring specialised multidisciplinary team care, including complex care coordination and psychological supports. State MND Associations provide services, supports, invaluable expertise and a comprehensive understanding of MND to ensure people living with MND can be supported to navigate the health system and access supports in a timely manner, commencing at the point of diagnosis through to end of life.

Response to the consultation paper

MND Australia appreciates the opportunity to respond to the consultation paper on the new framework planning. We would first like to register our disappointment that only two weeks separate the date referred with the closing date for submissions. For such major changes, we would expect a timeframe that allows for genuine government consultation and consideration of feedback. It is furthermore unreasonable and unrealistic to presume that a 289-page document can be adequately reviewed and consultation conducted within the given time frame by stakeholders and the community of NDIS participants.

What is missing from the proposed amendment

MND Australia and the MND State Associations are most concerned with what is not reflected in the amendment: The critical needs of people with a quickly-progressing, degenerative and terminal illness.

From 1 July 2024, the NDIS introduced significant improvements to the access and planning process to better support people living with MND. These changes were made in recognition of the complex needs of people living with MND and how quickly those needs can change. This ‘priority pathway’ has made a significant difference for people living with MND in accessing and navigating the NDIS when facing a terminal illness.

The MND priority pathway ensures that people under the age of 65 years who receive a diagnosis of MND can access NDIS assessors with knowledge of MND, who understand the likely progression of the disease, and who can provide an adequately-funded approved plan within days. These specialist MND assessors are also on hand to perform a re-assessment when a participant declines quickly. The priority pathway is supported by a dedicated and collaborative NDIS team, led by Skye Vale (NDIS Director, Priority Pathways). Skye meets monthly with the MND State Associations to ensure that services are timely appropriate, which has ensured its overwhelming success.

Prior to the establishment of the priority pathway, MND Australia and the MND State Associations lobbied for 10 years, advocating for a change in how younger Australians living with MND were interacting with the NDIS. Prior to the institution of the MND priority pathway, there were many instances of people who died prior to accessing plans, insufficient funding, and overall exceedingly poor and distressing outcomes. The ‘front door’ to the NDIS was not fit for purpose for this cohort.

The priority pathway for younger Australians diagnosed with MND, and other similar degenerative and terminal conditions, is not enshrined in legislation. If this access is removed, there is nowhere else for younger people living with MND to go. The health system is not designed to support individuals with intensive clinical needs, in need of expert care and whose decline is often rapid.

We are therefore asking:

1. **That the MND priority pathway be enshrined into the NDIS legislation.**
2. That the MND priority pathway continue to provide assessors with expert knowledge of MND, its expected trajectory, and an understanding of clinical and support needs.

3. That funding continue to be approved and released within under 30 days.
4. That reassessments continue to be made available as needed to this small cohort.
5. That reassessments continue to be made within a 21-day window.

The number of people who access the priority pathway is small. Between March 2024 – June 2025, NDIS data indicates only 784 people were accepted onto an NDIS plan via the priority pathway. While the data does not separate out the number of people with MND who utilised the pathway, they are included in an “Other” category which only numbers 91 people in that time frame.

Enshrining the priority pathway in the legislation would alleviate much stress and concern for younger Australians living with MND and their families, who worry about how the current legislation changes are going to impact on their ability to manage their disease.

The shift to measuring functional capacity (Schedule 1, Part 1 – Defining functional capacity)

MND generally progresses quickly. Within months, sometimes even weeks, someone can go from being mobile to requiring a wheelchair, lose the ability to swallow, start struggling to breathe, and/or find themselves no longer able to get out of bed.

A focus on functional capacity at a fixed point in time will work well for individuals with a stable disability, but will work directly against the progressive nature of MND, which requires a predictive ability in the assessment process. Changes in functional capacity need to be anticipated in order to match supports with need.

A pathway based on the diagnosis of MND ensures that the progressive degeneration of functional capacity is recognised and folded into the support plan.

The reduction in reassessments (Schedule 1 Part 2 – Limit unscheduled plan reassessments)

A focus on current functional capacity coupled with a stated intention to reduce the number of reassessments would be disastrous for people living with MND. Currently, when there are rapid degradations of an individual’s functional capacity they can be reassessed and their support plan adjusted to fit the new circumstances. Reducing access to timely reassessments coupled with a non-predictive assessment process leaves people experiencing functional decline without the supports they need at the time they need them.

MND Australia also finds it concerning that support coordinators and plan managers will no longer have the ability to request a reassessment. The MND State Associations undertake support coordination on behalf of many of their clients. Understandably, many people living with MND and their carers and families appreciate the assistance with pressing tasks, including requesting reassessments as needed. Some do not have a family member or carer to assist them, or the support network may not have the foresight to anticipate needs. Importantly, support coordinators bring a holistic approach and understanding to their role; this includes managing the complex system within which wrap-around care is provided, assisting with psychosocial support, and helping people to adjust to reduced capability and planning for what will be needed next. We request clarity on who may be authorised as a ‘plan nominee’[2] and suggest that individuals should be allowed to nominate a support coordinator or plan manager, with a, added verification process that the client and/or their carer or family member endorses the action on their behalf.

We also raise concerns that the proposed length of time provided to approve a reassessment has been extended dramatically, from 21 days to 90 days.[3] People living with MND cannot wait. If a reassessment has been requested, it is because the participant's situation has declined significantly.

Finally, NIDS participants need reassurance that a poor or inappropriate assessment, particularly with the introduction of automated decision making, can be challenged and reviewed in a fair, efficient and timely manner. Delays are highly problematic for people living with MND.

We therefore recommend that the approval window for a requested reassessment remain at 21 days.

Disregard for multiple impairments or comorbidities (Schedule 1, Part 3 – Strengthen link between an impairment and the need for support)

Schedule 1 Part 3[4] appears to be in direct contradiction with the shift away from a diagnosis-based approval framework to one that assesses functional capability. MND Australia requests a clearer demarcation between multiple impairments or comorbidities and an overall assessment of functional capability.

Reduction in funding supports to reduce NDIS spending (Schedule 1, Part 4-Support Determinations and Schedule 1, Part 6-Reasonable and necessary supports)

While there is broad public support for ensuring the NDIS remains financially viable, the government must ensure that cost savings do not eclipse the focus on participant need. This is particularly true for participants who are living with a disability that is degenerative, progressive and life-limiting. The proposed amendments in Part 4[5] and Part 6[6] to reduce funding amounts for core supports, capacity building, capital investments and recurring costs is likely to place many participants in a position in which they are unable to access necessary services. It is unconscionable to place necessary supports out of reach, particularly for NDIS participants who have fewer resources. This particular change is concerning in that it is likely to increase, rather than reduce, health inequities.

There is also potential for conditions such as MND to be disadvantaged by the evidence standard requirement. We request that specialist clinical protocols and endorsements be considered as acceptable evidence, particularly where there are gaps in knowledge.

MND Australia is also concerned that carer roles are presumed to remain constant. As MND progresses, the care burden exponentially increases. The trajectory is such that care needs increase and carers without added assistance are in danger of burnout or physical deterioration.

The ability to suspend plans (Schedule 1, Part 7-Plan suspensions etc.)

It is understandable that the NDIA should have the ability to suspend plans in reasonable circumstances. However, MND Australia and the State Associations are concerned with the wording, '…if a participant cannot be contacted or fails or refuses to respond to requests for information.'[7] Many NDIS participants, including people who have late-stage MND, have significant incapacities that should be considered in the legislation. We would like to see the legislation amended to specify that contact is attempted with not only the participant but also their plan nominee, support coordinator and plan manager. Many participants have barriers to regular communication, including many people who are living with MND. A reasonable approach to contact would include not only the participant but also the support network that surrounds them.

Permanence and treatment requirements (Schedule 1, Part 8 – Tightening meaning of permanence to reduce access where an impairment can be treated)

People diagnosed with MND receive various treatment, including from a neurologist specialising in motor neurone disease. While there is no doubt that MND is a permanent condition, we request that the diagnosis of MND be sufficient evidence to fulfil the requirements of proposed new section 25A, which requires that permanence of the impairment is evidenced through the exhaustion of all treatment options.

The use of automated decision-making (Schedule 3 Part 2)

MND Australia and the State Associations understand that use of automated decision-making can support thoughtful, informed decisions. We are concerned, in light of how the Integrated Assessment Tool was incorporated into Aged Care assessments, that NDIS participants are not subjected to similar inadequacies. We do appreciate the wording in the bill which implies there will be better safeguards in its use, including human oversight.[8]

We reiterate our position that was shared in our submission in response to the *public consultation on new framework planning*[9]:

MND Australia and the State Associations urge extreme caution in the over-use or over-reliance on automated decision technology or algorithms in the assessment and planning processes. Utilising technology should be limited to an assistive role in supporting decisions made by a skilled and knowledgeable assessment workforce. MND Australia requests clarity on whether there will be automated decision technology embedded in the new planning protocols. If so, it is expected that this is clearly detailed, including:

- what aspects of the assessment process are impacted
- what the guidelines are for automated decisions
- whether the automated decisions can be overturned and by whom, and
- what the appeals process is.

This is in line with the findings and recommendations of the Office of the Australian Information Commissioner.[10] The experience of automated decision technology embedded in the My Aged Care reforms have been extremely negative for people living with MND and despite reassurance poor decisions are unable to be overridden by staff.[11]

MND Australia and the State Associations are experts are delivering care and support services to people living with MND, their families and carers. We request careful consideration of the very real human impacts that automated decision technology has on the assessment process, particularly for people living with MND – a rapidly progressive, degenerative and terminal condition.

While many of the legislative changes to the NDIS are welcome, particularly those that target fraud and aim to increase provider accountability, the MND community is experiencing fear about how these changes will land for them. One of the guiding principles of the original Act was that “People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.”[12] MND Australia and the State Associations reiterate that changes to the NDIS, particularly those with an eye on reigning in expenses, should not be borne by participants. We are particularly concerned that the above planned changes to the NDIS that may impact on the NDIS experience of people living with MND would be a significant step backward in meeting their care and support needs. At this juncture, when the NDIS legislation is being amended, it is a ripe moment to enshrine the priority pathway for people diagnosed with a rapid, degenerative, life-limiting disease such as MND.

MND Australia would be happy to provide any further information, to discuss our submission with Taskforce Members, and/or present our views at one of the upcoming public hearings.

We look forward to hearing about the outcome of the consultation process.

Kind Regards,

Clare Sullivan
Chief Executive, MND Australia

mnd Australia   mnd New South Wales   mnd South Australia   mnd Western Australia
mnd Tasmania   mnd Queensland   mnd Victoria

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[1] MND Australia and Evohealth (2025). *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia.* Canberra. Access at https://www.mndaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf

[2] The Parliament of the Commonwealth of Australia (2026). National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026, p.17. p.19. Access at https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bId=r7487

[3] Ibid. p. 20.

[4] Ibid. p. 24.

[5] Ibid. p. 29.

[6] Ibid. p. 46.

[7] Ibid. p. 56.

[8] Ibid. p. 126.

[9] MND Australia (2026). “NDIS rules: Public consultation on new framework planning.” Submission made to the Department of Health, Disability and Ageing, 5 March 2026. Access at

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https://www.mndaustralia.org.au/getmedia/c4ff94cb-141a-4569-8c72-bde8e64e714f/NDIS-new-framework-planning-MNDA-Submission.pdf

[10] Office of the Australian Information Commissioner (2026). “Automated decision-making and public reporting under the Freedom of Information Act.” 21 January 2026. Access at https://www.oaic.gov.au/freedom-of-information/information-commissioner-decisions-and-reports/foi-reports/Automated-decision-making-and-public-reporting-under-the-Freedom-of-Information-Act

[11] MND Australia (2026). “Submission from MND Australia in support of the Senate Inquiry into The Transition of the Commonwealth Home Support Program to the Support at Home Program.” January 2026. Access at https://www.mndaustralia.org.au/getmedia/d3d7bac9-fbf2-4f87-aff0-7d4f8332c31e/Submission-addressing-the-transition-to-Support-at-Home-0126.pdf

[12] The Parliament of the Commonwealth of Australia (2013). National Disability Insurance Scheme Bill 2013, p. 5. Access at https://parlinfo.aph.gov.au/parlInfo/download/legislation/bills/r4946_third-reps/toc_pdf/12230b01.pdf;fileType=application%2Fpdf