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NDIA
Department of Health, Disability and Ageing
PO Box 6100
Parliament House Canberra ACT 2600

via email: NDISConsultations@health.gov.au

**RE: NDIS rules: Public consultation on new framework planning**

Thank you for the invitation to make a submission to the consultation on new framework planning. 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. 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.

**Response to the consultation paper**

MND Australia appreciates the opportunity to respond to the consultation paper on the new framework planning. In consultation with our State Associations, who are registered NDIS Providers, we have summarised a few key points, below, which complements the individual responses provided by the MND State Associations via survey response.

MND Australia appreciates that the new plans are intended to increase equity in the assessment process, and that the primary assessment tool, the I-CAN, is evidence based. However, our members and people living with MND have some concerns about the plans.

1. **Retention of the MND Priority Pathway.** The MND Priority Pathway has been a gift to people diagnosed with MND who otherwise have very little to celebrate. It has been extremely effective in ensuring that people living with MND receive the appropriate support in a timely manner. Assessments are conducted by professionals who understand MND and participants' needs, both at the time of assessment and as the disease progresses. From assessment to package plan approval is generally less than a week. Packages have good flexibility and allow for people living with MND to exercise choice and control as their condition progresses and their needs change, often rapidly. When a reassessment is necessary the expertise is at hand to oversee this process. The loss of this specialist knowledge and tailored, flexible supports would be devastating to people living with MND, their carers and families. The Fact Sheet for *Step 1: Preparing for a support needs assessment* states, "All NDIS participants must have a new framework plan within a five-year transition period as referenced in section 32C of the NDIS Act" (p. 2).[2]

   **MND Australia, the State Associations and people living with MND urge the NDIA to keep the priority pathway for people with MND.**

2. **Concerns with the I-CAN**. While the I-CAN is an evidence-based assessment tool that has undergone extensive testing and co-design, we have concerns with whether it would be appropriate for people living with MND.
   a. **The I-CAN does not appear to be predictive**. The description of the I-CAN provided and further reading about the tool indicates it is designed to assess current capabilities and needs. For people living with MND, where rapid disease progression needs to be considered in any plan, the lack of predictive capability is not fit for purpose.
   b. **The assessment meeting is too long**. Most people living with MND would not have the stamina to sit through a 3-hour, or indeed a 1-hour, assessment. Such timeframes would be exhausting. Depending on the progression of their disease, people living with MND struggle with extreme fatigue, inability to speak and difficulty breathing. Some people also experience significant cognitive decline caused by frontotemporal dementia. The MND priority pathways allows for an appropriate assessment process that is not taxing for people living with MND.

   **MND Australia requests that assessment options are provided that will fit the specific needs of people living with MND**.

3. **Specialist/medical reports should remain part of the assessment process.** MND Australia believes that there is still a role for specialist reports in the assessment process. We would like to see reports continue to be accepted, perhaps in specified

circumstances. These may include for individuals who cannot sit through a 3-hour assessment, for people whose needs will be rapidly changing, those who have a terminal illness, and/or in place of a reassessment meeting which could reduce the load on both assessors and participants.

4. **Assessors with specialist knowledge of MND should be retained.** While the assessors are described as allied health professionals, MND Australia is concerned if there were a loss of specialist skill and knowledge that the current MND assessors bring to their role. Because MND is rare and many health professionals will not see a case in their professional life, that expertise has been critical to ensuring appropriate support received by NDIS participants who are living with MND.

5. **Reassessments need to allow for both poor initial assessments and changing needs.** The guidelines for a reassessment appear inadequate for protection of participants' best interests. The fact sheet entitled *New framework planning rules: Step 2. The support needs assessment* states "A replacement assessment can only be requested before a plan is approved. NDIS delegates will make the decision on whether to undertake a replacement assessment or not" (p. 3).[3] With reassessments only allowed *prior to* a plan's approval, and the NDIS delegate holding the power to withhold a reassessment, the power is completely in the hands of the NDIS. This framework does not allow for a true dialogue or negotiation on the participants' needs and whether the plan will be adequate, undermining the NDIS values of empowerment, dignity and choice. This is particularly concerning when considering that people with disabilities may struggle in the assessment process. Additionally, it is unclear how the assessment/reassessment process accounts for rapidly changing needs, as experienced by people living with MND, particularly for assistive technology and equipment. Deterioration can occur over a matter of months, but the process described here would neither account for their changing needs nor have a pathway to request a reassessment to ensure the package reflects their needs in the moment. It is also unclear how often assessments will occur, the length of time of plans between assessments, and/or the length of package funding.

6. **Any use of automated decision technology/algorithms needs to be stated and transparent**. MND Australia urges 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.[4] 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;[5] in consequence MND Australia advises that it not be employed in any way. If they are to be used, we request complete transparency in their role and the criteria that guides decisions.

We would also like to request that in future the information for such important changes be provided in one easily-accessible place. It was difficult to find the relevant support materials for this consultation, which may impact on the quality and quantity of responses that are submitted.

MND Australia would be happy to provide any further information or to discuss our submission with Taskforce Members.

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

Kind Regards,

**Clare Sullivan**
Chief Executive, MND Australia

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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. https://www.mndaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf

[2] Department of Health, Disability and Ageing (2026). "New framework planning rules: Step 1. Preparing for a support needs assessment." January 2026. Available at https://consultations.health.gov.au/ndis/nfp-public-consultation/user_uploads/fact-sheet---step-1.-preparing-for-a-support-needs-assessment.pdf

[3] Department of Health, Disability and Ageing (2026). "New framework planning rules: Step 2. The support needs assessment." January 2026. Access at https://consultations.health.gov.au/ndis/nfp-public-consultation/user_uploads/fact-sheet---step-2.-the-support-needs-assessment.pdf

[4] 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

[5] 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