



RESEARCH
ADVOCACY
CURE



National Disability Insurance Scheme
Amendment (Getting the NDIS Back
on Track No. 1) Bill 2024 [Provisions]
Community Affairs Legislation Committee

MAY 2024



What is MS?

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

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.

Associate Professor Des Graham
President

Rohan Greenland
Chief Executive Officer

NDIS Amendment Bill

MS Australia welcomes the opportunity to provide a submission to the Legislation Committee on the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions] (NDIS Amendment Bill). Over the past nine years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS.

We have drafted a range of submissions relating to the NDIS, including five submissions to the *NDIS Review* and subsequent taskforce:

- [Submission to the NDIS Review](#) – December 2022
- [NDIS Quality & Safeguarding Framework](#) – May 2023
- [Pricing & Payment Approaches in the NDIS Market](#) – July 2023
- [What we have heard report – submission on solutions](#) – August 2023
- [NDIS Provider and Worker Registration Taskforce](#) – April 2024

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

MS Australia Recommendations

- The updated NDIS Act includes compulsory co-design for any significant changes to the NDIS Act and NDIS Rules and other legislative instruments
- The NDIA review and improve their current approach to co-design, including learnings from other sectors undergoing reforms
- The immediate establishment of a NDIS Review Implementation Advisory Committee as per Action 24.1 of the NDIS Review
- The Bill be updated to include a clear purpose for the new NDIA powers in relation to Section 30(2), Section 32 (F) and Section 32(H)
- The current NDIS supports, as outlined section 10(a),5 are replaced with a more appropriate definition that will allow for negotiation with state and territory governments and co-design with the disability sector before finalisation in the NDIS Rules.
- A power be included in the Bill for participants to seek an internal review of their needs assessment

MS Australia welcomes any improvements to the National Disability Insurance Scheme Act 2013 (NDIS Act) in response to the NDIS Review. However, we have concerns about the drafting and content of the NDIS Amendment Bill as outlined below.

Co-design

The NDIS Amendment Bill (Bill) was developed with very limited consultation with the disability sector. Changes to the NDIS should be done via a co-design process that draws on a range of views, skills, experience and interests across the disability community. People with disability should be at the centre of any decisions that will affect their lives.

As outlined in the Bill, a lot of the detail of the new NDIS will be in either the NDIS Rules or legislative instruments to be created by the Minister. This includes crucial elements of the Scheme such as the needs assessment process, the method for calculating budgets, how participants gain access to the Scheme, what supports are funded and how participants can spend their funding. The Explanatory Memorandum for the Bill indicates that these details will be designed in consultation with people with disability. Given the limited consultation on the Bill to date, it is crucial that co-design is clearly embedded into legislation. This will ensure that co-design is guaranteed regardless of which government and Minister has responsibility for the NDIS and can provide assurances for people living with disability.

MS Australia recommends that the updated NDIS Act includes compulsory co-design for any significant changes to the NDIS Act and NDIS Rules and other legislative instruments.

If the NDIA are committed to co-design for future NDIS reforms, there must be a substantial improvement in their co-design approach when implementing the outcomes of the NDIS review. The Bill was not accompanied by any easy-to-read materials, leaving people to read and interpret a long and complex Explanatory Memorandum. The accompanying NDIA webinar provided limited information on the Bill, presenters did not seem to be familiar with the materials they were presenting and very few audience questions were answered. The NDIA must review their current approach to co-design and work to improve this for future NDIS changes. Other sectors undergoing reform could provide some useful examples. In the aged care reform space webinars are more user friendly with lots of participant questions answered and consultations are usually accompanied by easy-to-read documentation. Additionally, the recent changes to the Aged Care Act were sent to stakeholders for review before entering the parliamentary process.

MS Australia recommends that the NDIA review and improve their current approach to co-design, including learnings from other sectors undergoing reforms.

The NDIS Review recommended that the Disability Reform Ministerial Council establish a NDIS Review Implementation Advisory Committee to monitor and advise on the initial period of implementation, including 'monitoring levels of engagement by the implementing agencies with people with disability'.¹ The Review recommended that membership of this Committee priorities people with disability, families and carers. The timely establishment of this Committee would ensure that people with disability have clear oversight of the implementation of reforms and the inclusion of people with disability.

MS Australia recommends the immediate establishment of a NDIS Review Implementation Advisory Committee as per Action 24.1 of the NDIS Review.

Delegated Legislation

As discussed above, a lot of the important detail of the new NDIS will be included in delegated legislation including the NDIS Rules and other legislative instruments to be created by the Minister. This lack of detail makes it very difficult to understand the full impact of the Bill and the proposed changes. Stakeholders must make assumptions about the purpose of each section and the intentions of the government. This is very concerning for the disability community, especially when there are some very substantial powers outlined in the Bill including the power for the NDIS to determine who manages a plan, how a participant spends their budget, what providers a participant gets their supports from and significant information gathering powers.

The NDIS review found that there has been a breakdown in trust between people with disability and the NDIA and that rebuilding trust is essential to fixing the NDIS. The Review made the following recommendation:

Action 3.6: The National Disability Insurance Agency should adopt a trust-based approach to oversight of how participants spend their budget, with a focus on providing guidance and support².

The current Bill as presented does not engender trust in the disability community and raises concerns about the lack of protections and the removal of choice and control. This could be improved by inserting further detail in the Bill on the purpose of these new powers. This would ensure that people understand the intention of each section and would also guide changes to the NDIS Rules and other legislative instruments. This should include the following:

- *Section 30(2) Information gathering powers* – this section should provide more detail on the circumstances that may result in the CEO requesting additional information and/or revoking a participant’s status.
- *Section 32 (F) Restrictions on plan management and flexible funding* – this section should provide more detail on the circumstances that would result in the NDIA restricting how a participant can spend flexible funding and/or denying a participant’s plan management request. The default position should be that participants have the right to determine who manages this plan and how they spend their flexible funding with restrictions reserved for instances where a participant is at risk of exploitation or abuse.
- *Section 32(H) Requirements for obtaining certain supports* – this section should provide more detail on the circumstances that result in the NDIA specifying where and how supports are obtained. The default position should be that participants have the right to determine where and how they receive their supports with restrictions reserved for the purchase of one-off expensive items or instances where a participant is at risk of exploitation or abuse.

MS Australia recommends that Bill be updated to include a clear purpose for the new NDIA powers in relation to Section 30(2), Section 32 (F) and Section 32(H).

NDIS Supports

The new NDIS supports outlined in Section 10(a) of the Bill move away from the current focus on ‘reasonable and necessary support’ towards a more defined list of supports with further detail to be outlined in the NDIS Rules (as agreed with state and territory governments). This list is based on selected elements in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is an important international human rights convention and should underpin all Australian legislation focused on Australians living with disability. However, MS Australia is concerned that the current approach in the Bill is highly restrictive, inconsistent and will limit what supports can be outlined in the NDIS rules. This includes:

- Highly restrictive wording such as ‘the support...is necessary to support the person to live and be included in the community, and to prevent isolation or segregation of the person from the community’
- The absence of some important elements of the CRPD including, including:
 - Article 19: The right to live independently - participants should get to choose the accommodation option that best suits their needs and wishes, including the option to live independently
 - Article 27: The right to equal access to work and employment – participants should be able to access employment support to allow them to undertake work
- The inclusion of health services and **habilitation** or rehabilitation services which are not currently covered by the NDIS and are generally considered supports provided by state and territory governments
- No allowance for household goods and equipment such as vacuum cleaners, e-bikes,

dishwashers and air conditioning. Access to these can be crucial for people living with MS. For example, many people living with MS suffers from temperature sensitivity and struggle to regulate their body temperature. Access to an air conditioner is the best way to manage this

- It is unclear where psychosocial supports fit into this definition
- Transitional provisions that rely on the Applied Principles and Tables of Support (APTOS) which is not optimal and is inconsistent with what is outlined in Section 10(a)

MS Australia recommends that the current NDIS supports as outlined in section 10(a) are replaced with a more appropriate definition that will allow for negotiation with state and territory governments and co-design with the disability sector before finalisation in the NDIS Rules.

Needs Assessment

Under the proposed changes to the NDIS, the new needs assessment will determine eligibility and provide the basis for a participants plan and budget. The experience of people living with MS accessing the NDIS has been that staff have a limited understanding of their disability and what supports they require. MS Australia is concerned that it will take substantial training and a long period of implementation to get the needs assessment process working effectively. However, there is currently no clear power in the Bill for a participant to seek an internal review of their needs assessment. It is crucial that this power is included and that participants know they can challenge the needs assessment if it is not accurate.

MS Australia recommends that a power be included in the Bill for participants to seek an internal review of their needs assessment.

Reference

¹ Commonwealth of Australia, Department of the Prime Minister and Cabinet (2023). *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report*. Retrieved from: <https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf>

² Commonwealth of Australia, Department of the Prime Minister and Cabinet (2023). *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report*. Retrieved from: <https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf>



RESEARCH
ADVOCACY
CURE