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NDIS General Issues Inquiry
*Joint Standing Committee on the
National Disability Insurance
Scheme*

JUNE 2023

SUBMISSION



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NDIS General Issues Inquiry

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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

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.

NDIS General Issues Inquiry

MS Australia welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme NDIS General Issues Inquiry and contribute to improving the NDIS to ensure it meets the needs of people with disability, including those living with MS. Over the past seven years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS. We have written over 28 submissions relating to the NDIS, including submissions to the NDIS/NDIA, the Joint Standing Committee on the NDIS, the Productivity Commission and the NDIS Review. Additionally, on 18 July 2022, MS Australia launched a campaign [A better NDIS for people living with MS](#) to highlight essential areas for reform in the NDIS.

Overall, MS Australia recognises that the NDIS provides crucial supports and has improved the lives of many people with disability, including those living with MS. MS Australia also acknowledges the \$732.9 million over 4 years allocated in the 2023-24 budget to support participant outcomes and the effective and sustainable operation of the Scheme. We also recognise the extensive work underway by the NDIS Review. However, we believe there are some outstanding issues to be addressed, with a particular focus on improving the understanding of disability (including MS), making it easier to navigate the NDIS, improving access to assistive technology and accommodation, improved planning and communication and more appropriate pricing.

MS Australia makes the following recommendations:

MS Australia Recommendations

The NDIA:

- Commit to educating and training all staff and contractors about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS.
- Establish a resource library of disability materials for use by NDIA staff that includes the MS Australia 'Snapshot'. Prior to a planning meeting, staff would use the library to access the materials relevant to the participant's disability.
- Compulsory disability awareness training for all NDIA staff with a focus on improved communication, planning and access for people with disability.
- Establish a Neurological Advisory Group to build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA.

The NDIA implement:

- Improved and timely access to assistive technology and accommodation with a focus on participant choice and control.
- A renewed focus on supporting young people with disability to leave residential aged care and an increase in the availability of age-appropriate specialist disability accommodation.

Improved processes for navigating the NDIS including:

- Improved and simplified pre-planning and access resources including best practice examples.
- Participants with progressive, degenerative, neurological and neuromuscular conditions such as MS are only required to have a plan review on an as needed basis.

- Planning meetings held over multiple sessions.
- Resources and training for health professionals in how to support patients accessing and navigating the NDIS.
- An increase nationally in the number of LACs and the introduction of compulsory minimum training standards for all LACs.
- Clear guidelines on which participants are eligible for support coordination.
- Reducing the unpaid advocacy burden on providers.

The NDIA adopt clearer and more timely communications to participants about decision-making processes, timelines and expectations.

An improved, clearly defined and streamlined early intervention pathway for adults with disability.

The NDIS implement a pricing schedule that fully funds the costs of delivering services and supporting participants. This includes prices that:

- Are consistent and indexed annually
- Take into consideration the cost of meeting the Schemes administrative and regulatory requirements
- Take into consideration all staffing costs including:
 - ❖ Paying staff in accordance with the SCHADS Industry Award and offering competitive wages
 - ❖ Costs of hiring allied health and other health professionals
 - ❖ Costs of recruiting and maintaining a well-skilled and experienced workforce
 - ❖ After-hours staffing costs
- Covers travel costs, especially in regional, rural and remote regions
- Cover the full costs of delivering groups supports

NDIS Understanding & Awareness

National Disability Insurance Agency (NDIA) staff do not have a good understanding of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. This leads to ineffective planning sessions, inappropriate plans that do not address needs and unnecessary reassessments or plan changes. There is also a lack of understanding of the importance of access to the coordination of supports and assistive technology for people living with MS.

Greater awareness, understanding and education of neurological and neuromuscular conditions are needed to ensure improved support, participant experience and outcomes. MS Australia has developed an MS 'Snapshot' in collaboration with the Disability Advocacy Network Australia (DANA) that provides a participant-informed, e-learning disability training package on MS for NDIA staff, but to date there is little evidence this resource is utilised.

NDIA staff also need to improve their understanding of disability and their capacity to appropriately engage with people with disability. Compulsory disability awareness training for all NDIA staff and an increase in staff with lived experience of disability will substantially improve

engagement with people with disability. It will also lead to improved application processes, person-centred plans, and reduced appeals and review requests.

Nearly 1.6 million Australians live with a progressive neurological or neuromuscular condition in Australia with an annual cost to the Australian economy of over \$36 billion. The [Neurological Alliance Of Australia \(NAA\)](#), of which MS Australia is a member, estimates that around 15% of NDIS participants have a progressive neurological or neuromuscular condition. MS Australia believes that creating a neurological voice within the advisory and consultative structure of the NDIA will ensure fairer representation for those living with progressive neurological or neuromuscular conditions and improve the understanding of the NDIA in relation to these conditions.

MS Australia recommends that the NDIA:

- Commit to educating and training all staff and contractors about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS.
- Establish a resource library of disability materials for use by NDIA staff that includes the MS Australia 'Snapshot'. Prior to a planning meeting, staff would use the library to access the materials relevant to the participant's disability.
- Compulsory disability awareness training for all NDIA staff with a focus on improved communication, planning and access for people with disability.
- Establish a Neurological Advisory Group to build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA

MS Australia notes that these recommendations align strongly with the Committees 'Capability and Culture of the NDIS Interim Report' which recommends that NDIA staff have:

Comprehensive training in disability awareness and anti-discrimination, and that the government support planners and other NDIA staff, including contact centre staff, to develop specialist skills in specific areas of disability and participants' needs, so the Scheme can serve the diversity of NDIS participants¹

Assistive Technology & Accommodation

Assistive technology and home modifications play a critical role in the lives of people living with MS by facilitating independence and participation in everyday activities. Access to appropriate accommodation is also crucial to people living with MS maintaining their independence. People should be able to choose the living arrangement that best meets their needs and long and short-term goals.

Feedback received by MS Australia indicates that people living with MS struggle to get approval for the assistive technology, home modifications and supported accommodation they need and to access it in a timely manner. Access to these supports is not driven by participant choice and control but by the decisions of planners and NDIS delegates. Planners often only approve assistive technology and home modifications that are immediately obvious to them and do not recognise that people with 'invisible' disabilities may have other needs. Planners also make assumptions about the accommodation needs of people living with MS, with a focus on shared accommodation or living with family members rather than the participants choice. There are also long delays in approvals for assistive technology and supported accommodation resulting in increased costs, faster disease progression, increased need for support and participant self-funding.

Many young people with disability live in aged care because there is nowhere else for them to live. MS Australia welcomed the release by the Australian Government of the *Younger People in Residential Aged Care Strategy 2020-25* and the commitment that by the end of 2025 no younger person (under the age of 65) is living in residential aged care unless there are exceptional circumstances. While there has been a substantial drop in the number of younger people entering

and living in residential aged care, the latest data² shows that the two targets set for 2022 have not been met. Given that these targets have not been met and there are still 2,934 people aged under 65 living in residential aged care in Australia, more resources need to be dedicated to supporting young people with disability to access the accommodation that best suits their needs and personal goals.

MS Australia recommends:

- Improved and timely access to assistive technology and accommodation with a focus on participant choice and control.
- A renewed focus on supporting young people with disability to leave residential aged care and an increase in the availability of age-appropriate specialist disability accommodation.

MS Australia acknowledges and welcomes the announcement in the recent Federal Budget of \$7.3 million in funding for a package of initiatives to further reduce the number of people under the age of 65 living in residential aged care.

Navigating the NDIS

For many people navigating the NDIS is complex, time consuming and overwhelming. People with disability and their families need support to access the Scheme and navigate the various stages of assessment, planning and service access. Most people living with MS will receive a diagnosis in adulthood and may have no previous experience interacting with the disability system and limited understanding of the disability providers and services in their area. They are also likely to be overwhelmed by their diagnosis and unsure of what supports and services they need.

The resources for people applying for the NDIS are inadequate and do not recognise the complexity of navigating the current system. Local Area Coordinators (LAC) provide inadequate support because they either do not have the appropriate skills and training or cover too large an area to provide individual support. Also, there is no information provided on the level and type of detail required in the access request and supporting evidence forms. Additionally, many medical professionals struggle to know what level of information is required and are overwhelmed by NDIS processes.

Currently, the NDIS requires participants to have their plan reassessed approximately every 12 months. For people living with MS, once they are assessed as eligible and receive an approved NDIS plan, the progressive, degenerative nature of MS means that their support needs will not decline over time. The requirement to have 12-monthly reviews is unnecessary, causes considerable stress for participants and in many instances can result in crucial services being removed or reduced. Additionally, for many people living with MS, fatigue, pain, 'brain fog' and memory issues can make planning meetings a tiring and overwhelming process. The ability to spread planning over several sessions would be a significant improvement and make the process more accessible for all people with disability.

Support coordination is an important component of the NDIS and provides participants with crucial support in managing their plan. The NDIS has no clear guidance on which participants will have support coordination approved in their plans. Feedback received by MS Australia indicates an inconsistency across planners, with no clear reason for why some participants do not get support coordination approved. Also, many participants have experienced plan reviews where their support coordination is removed or significantly reduced, causing great distress and limiting their ability to fully operationalise their plan. The gap in support coordination is often filled by providers delivering unfunded support and advocacy, leading to financial instability.

MS Australia recommends improved processes for navigating the NDIS including:

- Improved and simplified pre-planning and access resources including best practice examples.
- Participants with progressive, degenerative, neurological and neuromuscular conditions such as MS are only required to have a plan review on an as needed basis.
- Planning meetings held over multiple sessions.
- Resources and training for health professionals in how to support patients accessing and navigating the NDIS.
- An increase nationally in the number of LACs and the introduction of compulsory minimum training standards for all LACs.
- Clear guidelines on which participants are eligible for support coordination.
- Reducing the unpaid advocacy burden on providers.

MS Australia notes that the Minister for the NDIS, the Hon Bill Shorten MP, made an [address](#) to the National Press Club on 18 April 2023 in which he acknowledged that short-term planning is not working and that there is a need to move to multi-year plans that are:

more flexible and sustainable; freeing up more time to produce better plans that deliver better outcomes for people with disability – and more predictability for all involved.

Communication

Feedback from our Member Organisations also indicates that people living with MS struggle with the NDIA's poor communication around decision-making and timeframes including:

- Limited or no explanation for changes to plans, including cuts to essential supports
- Limited information around decision-making including a statement of reasons not being provided for failed access requests, internal reviews and complaints
- No clarity on timeframes for approvals, especially assistive technology and supported accommodation
- Constant change in NDIA contacts

MS Australia recommends that the NDIA adopt clearer and more timely communications to participants about decision-making processes, timelines and expectations.

Early Intervention

MS is an incurable, progressive condition and most people are on a trajectory to meet the Schemes full access criteria within their lifetime. Most people are diagnosed with MS between the ages of 20-40, with 75% being women. Often a diagnosis of MS occurs when people are fully employed, consolidating income, planning a family and/or making significant career choices. The early stages of MS are an ideal time for access to early intervention supports that allow them to continue working, being an active member of their community and slow the progression of their MS. Early intervention supports that can help people living with MS include (but are not limited to) allied health services, assistive technology and home modifications, psychological services and counselling and support coordination.

Feedback received by MS Australia indicates that the early intervention pathway for adults is

unclear and not well understood by planners and assessors. Many people do not know that they can access it, how it can support them, what supports are available and what evidence is needed to meet the criteria. Investing in a clear, streamlined early access pathway for adults with disability will slow the progression of their disability, allow them to continue in employment and community engagement, reduce carer burden and have long term economic benefits to the NDIS.

MS Australia recommends an improved, clearly defined and streamlined early intervention pathway for adults with disability

NDIS Pricing & Expenditure

The current NDIS pricing structure does not fully fund the costs of delivering services and supports under the Scheme. It does not adequately take into consideration costs related to meeting the administration and regulatory requirements of the Scheme, there are inconsistencies across the different pricing categories including and prices are not indexed annually

A high-quality disability workforce is crucial to ensuring that the Scheme delivers high-quality services and support to participants. Providers are currently struggling to recruit, maintain and train their workers due to the limits of the pricing structure which doesn't take these additional costs into account. Additionally, salaries in the care and support sector recently increased by approximately 4.7% in 2022 in line with the Social, Community, Home Care and Disability Services (SCHADS) Industry Award increases delivered via the Fair Work Ombudsman. Pricing also does not account for after-hours staffing costs and travel times and costs,

The underfunding of NDIS services means that providers must currently choose between delivering unfunded services (and risking financial instability) or delivering low quality/inadequate services.

MS Australia recommends the NDIS implement a pricing schedule that fully funds the costs of delivering services and supporting participants. This includes prices that:

- Are consistent and indexed annually
- Take into consideration the cost of meeting the Schemes administrative, registration and regulatory requirements
- Take into consideration the hours required to deliver plan management, support coordination and advocacy for participants
- Take into consideration all staffing costs including:
 - Paying staff in accordance with the SCHADS Industry Award and offering competitive wages
 - Costs of hiring allied health and other health professionals
 - Costs of recruiting and maintaining a well-skilled and experienced workforce
 - After-hours staffing costs
- Covers travel costs, especially in regional, rural and remote regions
- Cover the full costs of delivering group supports

Reference

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- ¹ Commonwealth of Australia (. 2023). Joint Standing Committee on the National Disability Insurance Scheme: Capability and Culture of the NDIA Interim Report. Retrieved from: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/CapabilityandCulture/Interim_Report
- ² Australian Institute of Health and Welfare (2022). *Younger people in residential aged care: GEN Aged Care Data Factsheet June 2022*. Retrieved from: <https://www.gen-agedcaredata.gov.au/Resources/Younger-people-in-residential-aged-care>

