

A BETTER ndis

FOR PEOPLE
LIVING WITH

MS

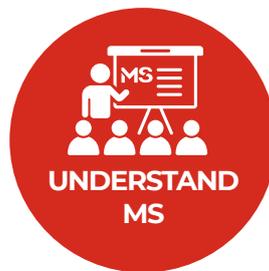


RESEARCH
ADVOCACY
CURE



CAMPAGNING FOR A
BETTER, FAIRER NDIS

MS Australia is campaigning for improvements to the National Disability Insurance Scheme (NDIS) to better meet the needs of people living with multiple sclerosis (MS).



To improve the NDIS for the MS community, we believe there are three essential areas for reform:

1. Better representation of people with MS and other progressive neurological conditions within the National Disability Insurance Agency (NDIA).
2. A better understanding of MS and the needs of people with MS.
3. Provision of disability supports and services regardless of age.

The NDIS is Australia's first publicly funded national disability insurance scheme. Legislated in 2013, and in full operation since 2020, the scheme has provided life-changing benefits to many Australians.

However, the NDIS is not without fault or its critics.

Over the last decade and across 28 policy submissions, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS.

For every positive story of an Australian helped by the Scheme, there are countless others who have been left behind.

Now with a new Government promising to rebuild trust in the NDIS, to ensure fairness and bring forward a review of the NDIS, originally scheduled for 2023, there are many reasons for optimism.

MS Australia stands ready to support the new Labor Government's intent for significant reform.



1

HEAR OUR VOICE

The 1.6 million Australians living with degenerative neurological or neuromuscular conditions deserve to be heard, understood, and effectively represented within the NDIA.

1.6 million Australians live with progressive, degenerative neurological or neuromuscular conditions. MS is calling for the neurological voice to be incorporated into the advisory and consultative structure of the NDIS/NDIA, to ensure fair representation and better support for our community.

How would that work?

1. Representation on the NDIA Industry Chief Executives Forum

The NDIA currently engages with NDIS provider peak bodies and provider representatives on improvements to the NDIS and the NDIA's processes and practices through the Industry Chief Executive Forum (ICE Forum)¹. The ICE Forum provides an opportunity for two-way collaboration where the NDIA can test policies, practices and processes to improve the NDIS with ICE Forum members and to gather views and feedback on key issues from Forum members.

The Forum also gives members the opportunity to engage directly with the NDIA CEO. There is currently no neurological or neuromuscular voice in the ICE Forum.

2. Establishment of an advisory group

The Autism Advisory Group² was established in 2018 to provide a strong voice on behalf of people with autism who participate in the NDIS. The group includes autism experts, service providers and people with lived experience of autism and advises the NDIA on autism.

A similar advisory group representing the neurological/neuromuscular community would be of enormous benefit to the NDIA.

The Neurological Alliance Australia (NAA) is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or neuromuscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Alliance Members are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia and Polio Australia.

1 <https://www.ndis.gov.au/about-us/reference-group-updates/industry-chief-executive-forum>

2 <https://www.ndis.gov.au/about-us/reference-group-updates/autism-advisory-group>

POLICY SOLUTION

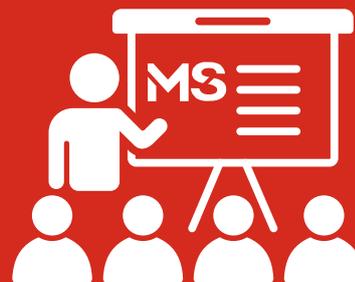
MS Australia recommends that:

1. A representative of the NAA be included on the existing NDIA Industry Chief Executives Forum.
2. A Neurological Advisory Group be established, similar to the Autism Advisory Group.

2

UNDERSTAND MS

The National Disability Insurance Agency (NDIA) can't offer solutions to what it doesn't fully understand. Better outcomes for people with MS requires greater training and education about MS within the NDIA.



Greater awareness, education and understanding of MS within the NDIA will ensure better support for people living with MS.

In February 2019, an 'MS Snapshot' was commissioned by the NDIA and developed by MS Australia to assist NDIA staff, such as planners or LACs (Local Area Coordinators), to better understand MS and improve their interactions with people with MS. It sets out the sort of information about MS one could reasonably expect NDIA staff to know.

Unfortunately, there is little evidence that this material has made any difference to the interactions of people with MS with the NDIA, especially those who experience invisible symptoms or symptoms that come and go.

A recent CSIRO publication in Australian Health Review entitled, "*Do people with multiple sclerosis receive appropriate support from the National Disability Insurance Scheme matching their level of disability? A description of disease burden and societal costs in people with multiple sclerosis in Australia (BAC-MS)*" published in September 2021³ is the first paper in Australia that correlates disability with the approved package value. The study has found 'striking variability in packages approved' citing restricted mobility as the main driver or decision-making factor. This appears to be consistent with the idea that visible disability is more easily understood than invisible disability or functional impairments such as cognition decline.

POLICY SOLUTION

MS Australia recommends that:

1. The NDIA commits to improving the understanding by NDIA staff and their contractors of the needs of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS, with a particular focus on recognising and addressing invisible symptoms, such as neuropathic pain, fatigue and cognitive issues.
2. Promulgation of the MS Snapshot and associated video provided by MS Australia in 2019 throughout the NDIA and its contractors
3. Introduce within the NDIA a substantial core group of staff (Neurological Community of Practice) with expertise in progressive degenerative, neurological and neuromuscular conditions that can act as a point for referral for all NDIA staff and contractors

³ <https://www.publish.csiro.au/ah/pdf/AH21056>

CASE STUDIES

Rebecca, 45, is an ex-health professional, and a single mother with a one-year-old child. She lives with her widowed mother who is 79. Rebecca's sister had to give up her work for eight months to care for Rebecca after post-partum progression. Rebecca has secondary progressive MS, EDSS of 4.5. She can't walk more than five metres unaided. She is at risk of falls and has fallen in the past. She experiences incontinence and has a clinical diagnosis of depression and anxiety. Rebecca has brain fog daily, chronic fatigue, processing difficulties, struggles to complete any paperwork, and word-finding difficulty.

Rebecca was contacted by the NDIS upon receipt of *access request form* to be asked "can you catch the bus and walk 10 metres?"; Rebecca answered that 'it would depend on the day' and was subsequently rejected over the phone.

3

DON'T DISCRIMINATE.

Chronic disease doesn't care about your age.
Nor should the NDIS!



All Australians with MS should be entitled to support from the NDIS regardless of their age.

Those aged 65 and over when the NDIS was introduced and those who develop a disability after turning 65 are ineligible for the NDIS and must pursue their disability needs through the aged care system.

This is a concern because the aged care system is designed to address frailty and dementia rather than the disability needs of people with MS, especially those whose progression of disability has been slowed or delayed through disease modifying treatments. This age cut-off has created a grossly inequitable two-tier system of support.

People outside the boundaries and eligibility of the NDIS, especially those living with fluctuating or episodic disability or chronic health conditions not deemed as permanent disability, are missing out.

Those living with neurological conditions or those living with mental health issues are experiencing gaps in service delivery, access and continuity of care. Supports are available only if self-funded or through the aged care sector, which is capped and means tested. This discrimination based on age is unacceptable and unfair.

The inequities between the aged care sector and the NDIS must be addressed.

People with MS aged 65 and over need adequate support to stay at home, engage in the community, stay at work with appropriate support and flexibility. This would ensure financial security is maintained to cater for such things as housing, aids and equipment and a quality social life. In general, aged care support has a much greater focus on personal care and in-home support rather than community participation – an important, often vital aspect of life for a person affected by a chronic condition such as MS.

POLICY SOLUTION

MS Australia recommends that:

1. Age discrimination for NDIS eligibility be abolished by amending the Age Discrimination Act and the NDIS Act to remove this inequity.
2. Implement recommendation 72 of the Aged Care Royal Commission, “Equity for people with disability receiving aged care by 1 July 2024”, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions.

CASE STUDIES

Lyn is 62 years old. Her husband Bob is 70 years old and has been living with MS for the past 30 years.

Because of the current discriminatory aged cut-off in place with NDIS, Bob can only access My Aged Care, which doesn't provide the same amount of assistance. Presently Bob has been waiting 15 months for any response to his approved aged care level 4 application. In that 15-month period, they have spent in excess of \$10,000 directly attributable to meeting Bob's needs. With an NDIS package, these costs would have been covered; with no requirement for co-payment.

Disability affects more than the person with the disease, it also has a huge impact on the life of the carer, as well as family. In this case, if Lyn was the one with MS, she would get an NDIS package and their quality of life would be a whole lot better off!



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About MS Australia

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.
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