



Capability and Culture of the NDIA

*Joint Standing Committee on the
National Disability Insurance
Scheme*

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SUBMISSION



AUSTRALIA

**RESEARCH
ADVOCACY
CURE**

Capability and Culture of the NDIA

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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 commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 25,600 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.

Capability and Culture of the NDIA

MS Australia welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) *Inquiry into the Capability and Culture of the NDIA*. Over the past seven years MS Australia has written over 27 submissions relating the NDIA and the NDIS, including 12 submissions to the Joint Standing Committee on the NDIS. This submission outlines the major outstanding issues from these submissions relating to the capability and culture of the NDIA and the experience of NDIS participants living with multiple sclerosis (MS) interacting with the NDIA.

MS Australia makes the following recommendations:

MS Australia Recommendations

- Commit to educating and training 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'
- Compulsory disability awareness training for all NDIA staff with a focus on improved communication, planning and access for people with disability
- Increase the number of NDIA staff who have lived experience of disability
- Adopt clearer and more timely communications to participants about decision-making processes, timelines and expectations.
- Establish a NDIA neurological advisory group

Improve Understanding of MS

MS Australia recognises that the NDIS provides crucial supports and has improved the lives of many people with disability, including those living with MS. However, MS Australia has concerns regarding the current understanding of NDIA staff about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS.

Feedback from our Member Organisations indicates that people with MS have found that the limited understanding by NDIA staff of neurological conditions leads to ineffective planning sessions, inconsistent plans that do not address their needs and unnecessary reassessments or plan changes. There is also a lack of understanding of the importance of access to coordination of supports and assistive technology for people living with MS. Greater awareness, understanding and education of neurological and neuromuscular conditions such as MS are needed to ensure improved support, participant experience and outcomes.

In 2019, MS Australia collaborated with the Disability Advocacy Network Australia (DANA) and the NDIA to develop a participant-informed, e-learning, disability training package on MS for NDIA staff, referred to as a 'Snapshot'. This included a fact sheet, four 'at a glance' examples, practical suggestions for engaging with people living with MS and a video which included participants speaking to NDIA staff about the disease and its impacts. Using the 'Snapshot' materials will improve the understanding of NDIA staff 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.

MS Australia recommends that the NDIA commit to educating and training staff and contractors about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. Greater awareness, education and understanding of MS within the NDIA will ensure better support for people living with MS.

MS Australia recommends that the NDIA 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. MS Australia would be very willing to engage with the NDIS on any further training or education materials required for the resource library.

Improve Disability Awareness & Understanding

Feedback from our Member Organisations indicates that people living with MS find NDIA staff do not have a good understanding of disability and are not well trained in how to appropriately engage with people with disability. There are also very few NDIA staff with lived experience of disability. The major concerns for people living with MS when engaging with NDIA staff are:

- Poor communication with participants including a lack of understanding of how the participants disability may impact their interactions. This includes the impact of fatigue, cognitive impairment and communication difficulties.
- Prejudging people by the way they look and/or sound and using this to determine what supports they need. This is especially concerning for those living with an 'invisible' disability such as MS.
- Limited preparation/pre-reading on the disability of the person they are meeting
- A lack of person-centred planning, including the inability to vary from a set of scripted questions
- Lack of understanding of how service types are interrelated, for example approving social supports but not the wheelchair or physiotherapy that is necessary for the person to access the social supports
- Failure to read reports provided by health professionals and service providers and/or dismissing their clinical observations and recommendations
- A focus on costs savings rather than participant outcomes or wellbeing.

MS Australia recommends compulsory disability awareness training for all NDIA staff with a focus on improved communication, planning and access for people with disability. Training should include:

- A background overview of disability including types of disability and how it impacts on a person's ability to complete everyday activities and engage in their community
- Communicating with people with disability including inclusive language and terminology
- Understanding the social, environmental and attitudinal barriers experienced by people with disability
- Understanding consent, decision making and choice for people with disability
- How to facilitate person-centred planning and creating plans with a focus on community participation and wellbeing

Improved disability awareness training for NDIA staff will lead to improved application processes, better plans that more accurately reflect the needs of the participant and reduced appeals and requests for reviews. On a broader level it will influence the NDIA's policies, resources,

communication and overall interaction with participants. This training can be further supported by ensuring that staff have a comprehensive understanding of the rules and regulations of the NDIA and how the NDIS interacts with the rest of the health system and other state/territory funded disability supports

MS Australia acknowledges the recent changes to the NDIA Board and the inclusion of more people with disability to oversee the work of the NDIA. This can be further improved by increasing the number of NDIA staff with lived experience of disability. People with lived experience of disability can bring a unique perspective to the NDIA and are better equipped to engage with people with disability and ensure they get the best outcome from the NDIS. It also increases confidence in the organisation and ensures the NDIA better reflects the cohort it represents.

MS Australia recommends the NDIA increase the number of NDIA staff who have lived experience of disability.

Communication with participants

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.

Better representation of people with MS and other progressive neurological conditions within the NDIA

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 establishing an NDIA neurological advisory group. The advisory group would seek to build greater awareness, education and understanding of progressive neurological and neuromuscular conditions within the NDIA. The establishment of an advisory group will contribute to ensuring the people living with these conditions gets access to the NDIS supports and services they need at the right time in their disease journey, reduce complaints, improve outcomes measures and ensure this population is treated equitably when accessing the NDIS.

MS Australia proposes that the Neurological Advisory Group would provide the NDIA with expert advice on the following issues:

- The most appropriate evidence-based model(s) for assessing NDIS eligibility and improving outcomes for people with neurological and neuromuscular conditions
- How the NDIS participant experience for people with neurological and neuromuscular conditions can be improved and better tailored for differing disease journeys

- How the skills of NDIA staff, Local Area Coordinators and Planners can be enhanced for the benefit of participants with neurological and neuromuscular conditions
- Systemic and other improvements that can be made to provide greater mainstream and community inclusion for people with neurological and neuromuscular conditions - both participants and non-participants

MS Australia supports the ongoing work of the Minister Shorten, the Department of Social Services and the NDIA to reform the NDIS and ensure that Australians with disability have access to the supports and services they need. Improving the capability and culture of the NDIA is an important step in this process and crucial to gaining the trust and support of Australians with disability. It can also become a workplace of choice for people with disability and a leader in the disability employment sector.

