



Submission to the Joint Standing Committee on the NDIS inquiry into the Capability and Culture of the NDIA

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Chair

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The Neurological Alliance Australia is an alliance of 15 not-for-profit peak or national patient organisations representing adults and children living with progressive neurological or neuromuscular diseases or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance 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, the Childhood Dementia Initiative, the Mito Foundation and Polio Australia.

Some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy

The Neurological Alliance Australia represents nearly 2 million Australians living with the conditions represented by the members of the Alliance with an annual impact on the Australian economy of over \$50 billion.

Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a submission to the Joint Standing Committee on the NDIS inquiry into the Capability and Culture of the NDIA.

The focus of the comments provided in this submission are on key areas that will impact on people affected by neurological disorders or progressive neurological and neuromuscular conditions for which our member organisations provide services, support and advocacy. Included are comments provided by our member organisations and, in some instances, directly from people living with those conditions represented by the NAA.

The [Neurological Alliance Australia](#) is an alliance of national not-for-profit peak or national patient organisations representing adults and children living with neurological disorders or progressive neurological and neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment in these diseases.

The Alliance represents nearly 2 million Australians living with these conditions that have no cure. This group includes adults and children, carers, families, friends and workmates whose lives have been affected by a progressive neurological or neuromuscular condition or a neurological disorder. The impact of neurological disorders and progressive neurological and neuromuscular conditions on individuals and families can undermine their resilience, which is a vital element of their ability to remain purposeful and in control of their lives in addition to preventing or minimising financial and emotional burden.

Progressive neurological and neuromuscular diseases and neurological disorders are a set of complex and disabling conditions. While this broad group contains conditions with various characteristics, different disease trajectories and life expectancy, nearly all are degenerative, all are incurable and few have proven treatments. This results in significant disability and the need for expert information, specialised care and personal assistance which is responsive to individual needs.

The Alliance works collaboratively to identify and advocate for opportunities that will drive improved quality of life for people living with these conditions and funding to support research.

Core issues

1. Neurological and neuromuscular conditions and neurological disorders are complex, and often degenerative and progressive. As such, support requirements do not reduce across time.

2. Neurological and neuromuscular disorders are generally poorly understood in the broader community, so our clients face a range of issues that potentially undermine social cohesion, and resilience (e.g. social stigma and exclusion).
3. These conditions and disorders may be poorly understood in health and disability settings, so clients face a range of interlocking issues that potentially undermine service level trust and resilience (e.g. misdiagnosis, delays, working with multiple practitioners simultaneously, feelings of not being believed).
4. Lack of NDIA staff knowledge and training affects the quality of assessment and care received by clients and their families (e.g. having to repeatedly explain their conditions, refusal of reasonable requests, inconsistent decision making, psychological impacts in part due to not being believed and respected).
5. To date, existing training materials about these conditions, appear not to have been widely used nor consistently applied.
6. People with neurological and neuromuscular conditions are not adequately represented on key advisory bodies.

Terms of Reference

The committee will inquire into and report on the implementation, performance, governance, administration and expenditure of the National Disability Insurance Scheme (NDIS), with particular reference to:

- a. the capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment
- b. the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency; and
- c. any other relevant matters.

Summary of recommendations

We recommend that the NDIA:

- 1. Commits to educating and training staff and contractors about the various neurological disorders and progressive, degenerative, neurological and neuromuscular conditions.**
- 2. Develops and implements a set of "guiding principles", with a focus on invisible symptoms (e.g. neuropathic pain, fatigue, post exertional malaise and cognitive issues)**
- 3. Minimises reassessments where the disease course is predictable**
- 4. Introduces a substantial core group of staff (a Neurological Community of Practice) with expertise in neurological disorders and progressive**

degenerative, neurological and neuromuscular conditions who can act as a point for referral for all NDIA staff and contractors.

- 5. Adopts clearer and more timely communications to participants about decision-making processes, timelines and expectations.**
- 6. Appoints a representative from the Neurological Alliance Australia to the Industry Chief Executives Forum**
- 7. Supports the establishment of a Neurological Advisory Group, similar to the Autism Advisory Group.**

Improving NDIS education about neurological/neuromuscular conditions

Greater awareness, education and understanding of neurological and neuromuscular conditions within the NDIA will ensure better support for people living with these conditions, responsive to individual needs and requirements. Many of the conditions represented by the NAA are progressive, degenerative and all are without a cure; many people often experience “invisible” symptoms and many have complex and unpredictable needs.

For example, many people with ME/CFS are unable to access the NDIS due to poor understanding of the disease (especially post-exertional malaise). For those with ME/CFS who do access the NDIS, the process seems to be an initial rejection of their application, which forces patients to appeal. Many obtain access following an appeal, which means they did meet the requirements initially. This causes a large amount of unnecessary stress, lost energy and expense.

Better education within the NDIA to improve understanding of people’s changing needs over time, will help address the frustration felt by NDIS applicants and participants in accessing NDIS support, and having to explain their condition repeatedly before moving on to the essential conversation about their inevitable increasing care needs and the increasing levels of functional impairment that the condition is causing. In some cases, if people can receive appropriate supports, it can allow their symptoms or disease progression to stabilise. Without appropriate supports, a person’s condition can deteriorate rapidly.

Establishing a set of guiding principles

A set of guiding principles for neurological and neuromuscular conditions should be established, and planners should receive education on how to implement them. This would improve consistency in assessment and provision of adequate supports. An example of one such principle could be that support is increased in a timely, responsive manner and that supports are not withdrawn, for those with neurological disorders or progressive neurodegenerative conditions and should not require an annual functional OT assessment to provide evidence of their diagnosis and ongoing support needs. This would reduce the need for as many assessments and reduce costs

(including unnecessary administrative appeals). This principle could be applied in particular to conditions such as the primary progressive form of MS and Machado-Joseph Disease, for example, where the disease course is fairly predictable. People with ME/CFS often experience little change in their symptoms from year to year and if any improvement was to occur, it typically takes years. A 5-year re-assessment may be more appropriate.

Disease-specific information and a Neurological Community of Practice

Several NAA member organisations (MND Australia in 2017, MS Australia in 2019 and Huntington's Australia in 2022) worked with the NDIA to develop and provide to the NDIA disease-specific "snapshots" to assist NDIA staff, such as planners or LACs (Local Area Coordinators), to better understand these conditions and improve their interactions with people living with Huntington's, MND and MS. The snapshots and accompanying videos set out the sort of information about these conditions one could reasonably expect NDIA staff to know.

Unfortunately, there is little evidence that this material has made any difference over time to interactions with people with MND or MS, especially those who experience invisible symptoms, symptoms that come and go or symptoms that rapidly progress.

We encourage the NDIA to expand this process with other neurological and neuromuscular diseases which the NAA represents, to ensure that NDIA staff have greater understanding of these conditions.

While the development of these materials was a good start, on their own they are insufficient to educate NDIA staff and shift interactions with people with neurological and neuromuscular conditions. For example, the MND Practice Guide is now *not* being well-utilised resulting in no consistent interactions with people with MND particularly when their condition rapidly deteriorates (noting that half die within two years of diagnosis).

Case study:

Person living with Motor Neurone Disease

Jeff waited three months after the report from his occupational therapist was submitted to the NDIS for a stand-up recliner chair. The delay was caused by the NDIS approval process rather than low stock from the supplier. This meant that Jeff could not sit in the lounge room if he was home by himself; he had to sit on or lay in bed during the day while his wife and kids were at work or school. If he did sit on the lounge, he had to rely on his wife or kids to lift him out of the chair. This impacted greatly on Jeff's independence.

Jeff's bathroom modifications took two years to complete after the original quotations and report had been submitted to the NDIS. A long list of circumstances caused this delay, primarily administration issues. A part of his Occupational Therapist report was to include a body dryer to allow him to shower in privacy without a carer. The NDIS denied the provision of this device with the option to dispute the decision. Jeff did dispute this decision, as it would set his bathroom renovations back a further three months. One of the verbal reasons the Review Committee gave was that Jeff did not need this device due

to the length of time that he had been living with Motor Neurone Disease. At that stage, he had been diagnosed for 2 ½ years and therefore would not likely need the equipment for long. The Case Manager informed Jeff that he could dispute this decision again, which would probably take another three months.

After two years the bathroom renovation suits all of Jeff needs, but while decisions were caught up in “red tape”, he lost his independence to enable him to shower alone in privacy.

If this material was used by assessors, many other organisations would like to develop similar guides for their diseases, many of whom struggle to gain access to the NDIS due to poor understanding of their disease.

We encourage the NDIA to invest in education and to revisit the establishment of a Neurological Community of Practice, an initiative which had the potential to create change in NDIA’s approach to these conditions.

In 2020 the NDIA commenced the establishment of a Neurological Community of Practice (led out of the NDIA Head Office in Geelong) with the goal of establishing principles to guide planners as they work with participants with these conditions. This initiative was subsequently abandoned with no communication or consultation.

Case study

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, EDSS¹ 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, cognitive processing difficulties and word-finding difficulty, and struggles to complete any paperwork.

Rebecca was contacted by the NDIA 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.

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 2021¹ correlates disability with the approved package value. The study has found ‘striking variability in packages approved’ citing

¹The Expanded Disability Status Scale (EDSS) is a method of quantifying physical disability in multiple sclerosis and monitoring changes in the level of disability over time. It is widely used in clinical trials and in the assessment of people with MS. The EDSS scale ranges from 0 to 10 in 0.5 unit increments that represent higher levels of disability. Scoring is based on an examination by a neurologist.

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.²

Case study:

Kelly Engelhardt, 41, was first diagnosed with multiple sclerosis in July 2001, while studying teaching at university. Her teaching career was cut short as her condition worsened.

Married with two children, Kelly has now been receiving NDIS support for five years after her first application was denied.

While enormously grateful for the support, Kelly is frustrated by the NDIA's lack of understanding about her condition.

"I was out at the shops, and I just burst into tears. And I spoke to my neurologist, and he was like, 'Are you kidding me? They are asking you for proof that you can't be cured?' So it was really deflating. If they (the NDIS) don't understand about it not being cured, how are they going to understand what help I need."

"We all have different types of MS, within those different types we all have different degrees of disability and you need to understand everybody's case is completely different for what we need to make our lives better."

Kelly's mobility has dramatically declined in the last three years, and she requires the use of a wheelchair when leaving the house. Four months ago it was hard to go to the local shopping centre but she could do it. Now it has become too challenging and the impact on her health too great.

"I'm fatigued all the time, always so tired. It's the fatigue, the pain...I forget things easily."

In her most recent NDIS assessment, Kelly was left disappointed and baffled that her request to increase her access to an exercise physiotherapist from one hour a week to two hours a week was knocked back this year.

"I never wanted to stop working, I never wanted to rely on the government to help me with things. I am exceptionally grateful that the NDIS exists, more than I could ever explain, because it helps me. But I need help in some ways that are missing from the NDIS. To give me hope that the decline can slow down, that I can be a better mum and wife for as long as I possibly can."

Case study:

Daniel, a man living with the degenerative neurological condition Machado-Joseph Disease was funded for 2:1 ratio of supports 24/7 in his NDIS plan from 2018. Evidence was provided through an OT functional report, and subsequent reports were provided in later years demonstrating his functional decline. In 2021 the NDIA cut his funding to cover 1:1 ratio of supports only.

His Support Coordinator (MJD Foundation) communicated this as a 'catastrophic risk' to the participant and refused to direct his SIL provider to reduce the ratio of supports. In going through NDIA processes, a 12-month-old OT functional assessment report was deemed to be 'out of date' and could not be used as evidence. With a wait list for another

² Lechner-Scott et al, *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 cost in people with multiple sclerosis in Australia'* (BAC-MS), Australian Health Review, 2021, 45, 745-752
<https://www.publish.csiro.au/ah/AH21056>, 21 Sept 2021

OT functional assessment many months long, Daniel will run out of funding 3 months before his NDIS plan date.

In response to this issue, the NDIA has stated that the MJDF must fund the difference between 2:1 and 1:1 supports, despite the fact that his NDIS plan previously funded this for many years and he has a degenerative condition.

Inconsistent decision-making leading to plan inequities

A lack of understanding of the complexities of neurological and neuromuscular conditions can lead to inconsistent decision-making and inequities in plans.

For example, a lack of understanding of mitochondrial disease (mito) leads to a focus on more easily understood disabilities, usually sensory. People with mito are being accepted into NDIS because of their early presenting vision and/or hearing impairments. Then, when their underlying condition (mito) progresses, they face the unusual process of 'adding a disability', even though their underlying condition has not changed, but simply progressed.

In some cases, cognitive disabilities are not appropriately considered in interactions with participants. For example, in the case where an applicant was contacted directly by the NDIA and then minimised the impact of their disabilities despite evidence of cognitive impact being provided. This conversation is thought to have been influential in the decision to deny this person access to the scheme.

In addition, now that case management support has ceased, (which was assisting people to navigate health and support systems and advocacy processes) and following the merging/removal of level 2 and 3 high intensity conditions (in July 2022), adverse consequences have arisen whereby an overall increase in funding has occurred but not for level 3 specifically.

Accessing “complex support coordination” (level 3 provides an extra \$90/hour) is difficult once general support coordination has been allocated – this is inconsistently applied by the NDIA, and funding depends on the knowledge of the particular NDIA planner, leading to inconsistencies in outcomes. Huntington’s Australia estimates that 70% of their support coordination work is at level 3 but 98% of funding is at level 2. (This estimate is supported by an independent NDIS accreditor.)

Increased understanding of intersection with mainstream supports such as Palliative Care

Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. A *palliative approach* shifts the primary focus from life-prolonging treatments towards symptom treatment and quality of remaining life. End-of-life care is

focused on providing increased services and support for the person's physical, emotional, social and spiritual/existential issues as they approach death.

It is important for NDIA Planner education to incorporate education regarding a best practice palliative approach to care for people living with progressive, degenerative, neurological conditions and to understand the distinction from end-of-life palliative care (which the NDIS makes clear is the responsibility of the healthcare system).

One of the NAA members consistently experiences planners threatening to cut NDIS supports if a palliative care team is involved even for a single consultation around Advanced Care Planning.

Recommendations

We recommend that the NDIA:

- 1. Commits to educating and training staff and contractors about the various neurological disorders and progressive, degenerative, neurological and neuromuscular conditions.**
- 2. Develops and implements a set of "guiding principles", with a focus on invisible symptoms (e.g. neuropathic pain, fatigue, post exertional malaise and cognitive issues)**
- 3. Minimises reassessments where the disease course is predictable**
- 4. Introduces a substantial core group of staff (a Neurological Community of Practice) with expertise in neurological disorders and progressive degenerative, neurological and neuromuscular conditions who can act as a point for referral for all NDIA staff and contractors.**

Improving communications from the NDIA

Participants sometimes feel that the supporting documentation they've obtained from neurologists and allied health professionals, often at great expense, time and effort, is neither understood nor taken into account by NDIA decision-makers. This material is essential to the care and wellbeing of the participant, as interventions by healthcare professionals as soon as possible after diagnosis can often slow the progression of disability and thus the quantity of NDIS funds required. For poorly understood diseases with no biomarkers or approved treatments, these supporting documents are an essential part of building the case of disability and need for NDIS support. People with neurological and neuromuscular conditions or neurological disorders need the right supports at the right time.

Some people are unable to clearly articulate their own condition or their own needs over time, so the burden of explanation falls on family members and carers. There is an inequitable emphasis on self-advocacy; people without a

support network and those with cognitive and behavioural challenges do poorly in NDIS assessment processes.

Participants do not always understand why their access has been denied or their plans cut. The NDIA needs to adopt clearer and more timely communications to participants about decision-making processes, timelines and expectations. This includes general information provided on the NDIA website and plain English communications with individual applicants and participants.

Recommendations

We recommend that the NDIA:

5. Adopts clearer and more timely communications to participants about decision-making processes, timelines and expectations.

Access to specialist services

People with neurological and neuromuscular diseases usually prefer to access specialist services and supports from providers who understand and have long-standing expertise in their condition. Specialist, expert services and support also lead to better outcomes for participants.

The focus of the NDIA on gaining efficiencies by utilising large providers often means smaller, specialist providers cannot break even, especially if they are providing high quality, though small, allied health and support coordination services. A good example of this limitation on smaller providers is the 30-minute travel time claim limit for the time spent travelling to each participant, as set out in the NDIS Pricing Arrangements and Price Limits 2022-23.

This limits participants' choice and access to specialist expertise, and this in turn will lead to a smaller number of large, national, generalist providers and a reduction in specialist, expert services overall which may result in poorer and more costly outcomes overall.

Establishing a neurological/neuromuscular voice within the NDIA

The establishment of a neurological/neuromuscular voice within the advisory and consultative structure of the NDIA would ensure fair representation and better support for our community and help to address many of the issues set out in this submission in a constructive, co-operative way. The "neurological/neuromuscular voice" could be achieved in two ways:

A. 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). There is currently no neurological or neuromuscular voice on the ICE Forum.

Neurological and neuromuscular representation on the ICE Forum would provide our disease groups the same opportunity for two-way collaboration as other organisations represented on ICE. This would assist the NDIA to test policies, practices and processes to improve the NDIS and to gather views and feedback on key issues.

The Forum would also give the NDIA CEO the opportunity to engage directly with neurological and neuromuscular voices, which would assist in improving understanding of these diseases and patient needs.

B. Establishment of a neurological/neuromuscular advisory group (similar to the Autism Advisory Group (AAG))

The Autism Advisory Group was established in 2018 to provide a strong voice on behalf of people 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, to provide advice and recommendations on improving the NDIS for participants living with these conditions. The Neurological Alliance Australia (NAA) is keen to assist the NDIA with the establishment of this advisory group.

Recommendations

We recommend that the NDIA:

- 6. Appoints a representative from the Neurological Alliance Australia to the Industry Chief Executives Forum**
- 7. Supports the establishment of a Neurological Advisory Group, similar to the Autism Advisory Group.**

Conclusion

In conclusion, the Neurological Alliance Australia (NAA) is pleased to provide a submission to the Joint Standing Committee on the NDIS inquiry into the Capability and Culture of the NDIA. We look forward to working with the Joint Standing Committee, the Minister and the NDIA to make constructive suggestions for implementing improvements to the NDIS to ensure the aims and objectives of the NDIS are realised for people living with neurological and neuromuscular conditions.