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# Submission to the Joint Standing Committee on the NDIS inquiry into the NDIS participant experience in rural, regional and remote Australia

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23 February 2024

**Rohan Greenland**  
**Chair**

**David Ali**  
**Deputy Chair**

***The Neurological Alliance Australia** is an alliance of 21 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: the Brain Foundation, Brain Injury Australia, the Childhood Dementia Initiative, Dementia Australia, Emerge Australia, Epilepsy Australia, Epilepsy Foundation, Fragile X Association of Australia, Huntington's Australia, Leukodystrophy Australia, Migraine Australia, the Mito Foundation, MJD Foundation, Motor Neurone Disease (MND) Australia, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Myasthenia (Gravis) Alliance Australia, Parkinson's Australia, Polio Australia and Spinal Muscular Atrophy Australia, Polio Australia.*

***The Neurological Alliance Australia** represents the approximately 1 in 6 Australians<sup>1</sup> living with neurological or neuromuscular conditions or neurological disorders with an annual impact on the Australian economy of over \$100 billion<sup>2</sup>.*

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<sup>1</sup> Based on WHO global study: *Neurological Disorders: Public Health Challenges*, A World Health Organisation Report retrieved from: <https://www.who.int/publications/i/item/9789241563369>

<sup>2</sup> Based on an aggregation of data from organisations who have commissioned economic impact studies

## Summary of recommendations

The Neurological Alliance Australia (NAA) recommends:

- 1. That the NDIA commits to educating and training staff and contractors about the various functional impairments that arise from being diagnosed with neurological disorders and progressive, degenerative, neurological and neuromuscular conditions including issues of stigma and social exclusion that occur in rural, regional and remote settings.**
- 2. That the Government accepts the NDIS Review recommendation for NDIS eligibility to be based on functional impairment (Action 3.1)<sup>3</sup> rather than medical diagnosis and that standardised methods for assessing functional capacity underpin this.**
- 3. That the NDIA develops and implements a set of "guiding principles", with a focus on invisible symptoms (e.g. neuropathic pain, fatigue, post exertional malaise, migraine and cognitive issues) including special provisions for those living in rural, regional and remote locations.**
- 4. That the NDIA minimises reassessments where the disease course and level of functional impairment is predictable**
- 5. That the NDIA 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.**
- 6. That the NDIA adopts clearer and more timely communications to participants about decision-making processes, timelines and expectations.**
- 7. That the NDIA establishes a Neurological Working Group**

## Introduction

The NAA is pleased to provide this submission to the Joint Standing Committee on the NDIS inquiry into the NDIS participant experience in rural, regional and remote 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 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 in rural, regional and remote locations, for which our member organisations provide services, support and advocacy. Included are comments provided by our member organisations

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<sup>3</sup> <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/preface/recommendations-and-actions>

and, in some instances, directly from people living with those conditions represented by the NAA.

These conditions represent around 14% of NDIS participants<sup>4</sup>.

The NAA was established in 2010 to promote improved quality of life, coordinated services and greater research investment in 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 often resulting in severe functional impairment. 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.

## Terms of reference

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on the NDIS participant experience in rural, regional and remote Australia, with particular reference to:

- a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;
- b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;
- c. participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;
- d. the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS; and
- e. any other related matters.

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<sup>4</sup> Based on an aggregation of neurological 'primary disability groups' in the NDIS quarterly reports <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

## Rural, regional and remote health challenges

Challenges faced by NDIS participants living in rural, regional and remote areas of Australia have much in common with their healthcare challenges.

According to an AIHW web article, “Rural and remote health”, dated 13 September 2023,

“Around 7 million people – or 28% of the Australian population – live in rural and remote areas, which encompass many diverse locations and communities (ABS 2022e). These Australians face unique challenges due to their geographic location and often have poorer health outcomes than people living in metropolitan areas. Data show that people living in rural and remote areas have higher rates of hospitalisations, deaths, injury and also have poorer access to, and use of, primary health care services, than people living in *Major cities*.”<sup>5</sup>

Common healthcare challenges faced by individuals with neurological and neuromuscular conditions and disorders in rural, regional and remote areas are:

1. Limited access to specialised care: Rural and isolated areas often have fewer healthcare facilities and specialists. Access to neurologists, rehabilitation and allied health services, and other specialists are limited, requiring individuals to travel long distances to receive appropriate care.
2. Geographical barriers: Remote locations can present significant challenges for individuals seeking healthcare. Transportation difficulties and long travel times can contribute to delays in diagnosis, treatment, and ongoing management of neurological conditions.
3. Health workforce shortages: Rural areas experience shortages of healthcare professionals, including neurologists, physiotherapists, and occupational therapists. This shortage can result in longer waiting times for appointments and a lack of continuity of care.
4. Limited rehabilitation services: Access to rehabilitation services, such as physical and occupational therapy, is restricted in rural areas. This limitation can impact the ability of individuals with neurological conditions to maximise their functional abilities and improve their quality of life.
5. Social isolation: Rural and isolated areas may lack local support networks for individuals with neurological conditions. Social isolation can contribute to mental health challenges and impact overall well-being.
6. Telehealth challenges: While telehealth has become more prevalent, reliable internet connectivity and lack of appropriate IT equipment and knowledge in remote areas can be a barrier to accessing virtual healthcare

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<sup>5</sup> AIHW web article, “Rural and remote health”, 13 Sept 2023: <https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health>

services. This may limit the effectiveness of telehealth solutions for individuals with neurological and neuromuscular conditions.

7. Community awareness: There may be a lack of awareness and understanding of neurological and neuromuscular conditions within rural, regional and remote communities. This can lead to stigmatisation and social exclusion and hinder the provision of appropriate support services.

Many of these healthcare challenges in rural, regional and remote areas of Australia are replicated in the NDIS participant experience.

## **Research into the NDIS participant experience in rural, regional and remote Australia**

An analysis of recent research<sup>6,7,8</sup> into the NDIS participant experience in rural, regional and remote Australia reveals a number of consistent themes:

### **Limited access to supports in remote and very remote areas (otherwise known as “thin markets”)**

There are insufficient service providers and professional supports, especially allied health providers and lack of access to expertise in neurological conditions. This leads to underutilisation of plans.

This challenge was identified in the report of the Joint Standing Committee on the NDIS inquiry into NDIS Planning in 2020, that stated,

“An issue for participants in rural and remote areas is a lack of service providers to provide the supports that participants are funded for in their plans, leading to low plan utilisation rates and the possibility of a decrease in funding in participants’ subsequent plans. As a result, service providers that do exist in rural and remote areas may feature long wait times and long waiting lists for services.”<sup>9</sup>

### **Insufficient, poorly trained and transient workforce**

- isolation of NDIS participants living in rural and remote areas during the initial stages of the NDIS planning process. The research publications reported that people with disability felt that LACs and NDIA planners have

<sup>6</sup> Veli-Gold S, Gilroy J, Wright W, Bulkeley K, Jensen H, Dew A, et al. The experiences of people with disability and their families/carers navigating the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. *Aust J Rural Health*. 2023; 31: 631–647. <https://doi.org/10.1111/ajr.13011>

<sup>7</sup> Gilroy J, Veli-Gold S, Wright W, Dew A, Jensen H, Bulkeley K, et al. Disability workforce and the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. *Aust J Rural Health*. 2023;31:839–854. <https://doi.org/10.1111/ajr.13020>

<sup>8</sup> Wakely L, Green E, Little A, Fisher K, Wakely K, Currie K, et al. The lived experience of receiving services as a National Disability Insurance Scheme participant in a rural area: Challenges of choice and control. *Aust J Rural Health*. 2023; 31: 648–658. <https://doi.org/10.1111/ajr.13000>

<sup>9</sup> Joint Standing Committee on the NDIS (JSC) Inquiry into NDIS Planning (2020), Chapter 9 [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/NDISPlanning/Final\\_Report](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/NDISPlanning/Final_Report)

a lack of awareness on the barriers to specialised services for people with disability living in these geographical locations.

- people requiring services must either travel to a hub or regulate their lifestyle to reflect the agency values or operations and therefore limiting choice and control of disability services. Workers based in hubs may also deliver out-reach services to outlying rural and remote locations. Fly-in, fly-out (FIFO) and drive-in, drive-out (DIDO) are also common rural/remote service delivery models providing specialist input via workers making short-duration visits to communities. Both models have challenges due to the high cost of delivery, their infrequent and time-limited nature and typically high staff turnover. Although the disability services workforce has increased in size with the advent of the NDIS, in regional, rural and remote regions it still predominately operates on a FIFO/DIDO model.
- lack of individual choice and control over the NDIS planning process within these geographical locations was reportedly due to multiple factors, including a transient health/NDIA workforce, staffing shortages, and low capacity of service providers/NDIA staff within these regions
- cases of NDIA planners declining participants requests for specific supports despite the plan drawing on professional advice/reports from qualified health professions, such as occupational therapists and physiotherapists. Two studies noted that these occurrences of rejected allied health/medical profession input were related to the lack of awareness of NDIA workers.
- studies also reported the negative impact that transient health workforce and inexperienced NDIA staff can have on the emotional burden of NDIS package holders and carers during the planning process. These findings supported previous studies conducted into the impacts of transient health workforce in rural and remote settings across Australia.

### **Workforce pressures**

- NDIS staff and allied health workers in regional, rural and remote regions reported the complexity of engaging with the NDIS process resulted in an increased administrative burden on all staff involved.
- pressure on staff due to very high and increasing caseloads.

### **Community education regarding the NDIS**

- NDIS applicants living in regional, rural or remote areas were uninformed about the NDIS and unaware of how to find information.
- when contacting the NDIA for assistance, participants were only directed to the website that remains difficult to navigate and lacks any alternative formats such as languages other than English, Australian sign language (Auslan) or Easy read.
- relationship between people's education attainment levels, socio-economic status, main spoken language, and regional location and their ability to self-advocate during the NDIS planning process. The access to already existing social capital and geographic capacity within urban areas



led to better advocacy skills during the planning process and consequently higher levels of funding.

### **Concerns from First Nations communities**

- local Aboriginal and Torres Strait Islander communities in regional, rural and remote settings were identified as struggling to understand the NDIS and the definition of disability.
- one study identified the reluctance of Aboriginal and Torres Strait Islander people with disability to access the NDIS due to historical distrust of governmental services.

### **Travel and accommodation issues**

- lack of funding to cover required travel during the NDIS planning process
- many package holders' plans did not adequately accommodate travel costs required to conduct the planning process, such as attending meetings with allied health services, medical facilities and other required evidence to inform the development of the plan. Although NDIS packages include some funds for the cost of therapists and NDIA staff travel, they did not include funding for NDIS package holders and their carers to travel for appointments. Consequently, some families reported that they were not able to attend meetings/therapy sessions to properly complete the planning process.
- inadequate travel allowance was a major finding throughout the research papers for NDIS package holders, who reported that this was largely due to LACs and planners lack of understanding of the geographical distances between rural, regional and remote communities.

### **Carer concerns**

- Carers in regional, rural or remote areas reported feeling overwhelmed by the competing nature of running a family household, navigating the complexities of the NDIS and travel. The financial and emotional burden of travelling large distances for health care services was identified as having psychological impact on carers and NDIS package holders.

### **Internet access**

- regional, rural and remote areas had the added complication of limited access to the Internet, diminishing online engagement with NDIA and with allied health providers.

## **NDIA's approach to improving NDIS support in rural, regional and remote Australia**

NDIA strategies to improve NDIS support in rural, regional and remote areas could be summarised as follows:

## NDIA Rural and Remote Strategy 2016

The NDIA Rural and Remote Strategy (Strategy) was developed in 2016 to guide the roll out of the NDIS in rural and remote Australia during transition<sup>10</sup>.

According to the latest NDIA quarterly report, 9,556 participants (1.5%) live in remote and very remote areas.

In June 2020, the NDIA released the Participants across the remoteness classification report<sup>11</sup>. This report aims to provide valuable insights into the experience and the profile of participants, their carers and their families.

It is designed to deliver:

- Better outcomes at a whole-of-community level through implementing a place-based approach, delivering participant outcomes and facilitating solutions.
- Quality participant plans that include culturally relevant supports.
- Coordinating across all government levels to maximise NDIS scheme outcomes
- Access to specific services or markets at a whole-of-region level through thin market trails and alternative commissioning approaches.
- Improving the economic and social outcomes for participants by addressing existing supply gaps at a local level, including using alternative commissioning for supports where necessary and enhanced coordination between disability and mainstream services.

## Higher Price Limits for Supports in Remote and Very Remote areas

The NDIS Price Guide stipulates and guides higher price limits for specific supports in remote and very remote areas. This is a response to the higher operational costs of delivering services in these areas. From July 1st 2019, loadings increased from 20% to 40% for remote participants and 25% to 50% for very remote participants. From 1 July 2020, the NDIS price guide introduced more changes to provide travel rules to help improve the providers' ability to claim non-labour costs associated with travel. These changes were designed to encourage a broader service delivery and improved choice for regional and remote participants to access NDIS supports.

## Remote Community Connectors

The role of "community connectors" as "trusted community members" has been established by the NDIA, created to play a key role in identifying and engaging people with disability and their representatives. In March 2021, the NDIA employed 173 Remote Community Connectors that covered 274 rural and remote communities with over 90 Local Government Areas throughout WA, SA, NT, and QLD.

<sup>10</sup> <https://www.ndis.gov.au/about-us/strategies/rural-and-remote-strategy>

<sup>11</sup> <https://data.ndis.gov.au/reports-and-analyses/participant-dashboards/previous-participant-group-reports>



## **Better NDIS Services Via Aboriginal Community-Controlled Health Organisations**

The Australian government has invested over \$5.9 million in the NDIS Ready project to increase the number of Aboriginal Community Controlled Health Organisations registered to deliver NDIS services. Through the NDIS Ready project, the NACCHO is working with affiliates, NDIS Plan managers and Community Controlled Health Organisations to increase the supply of culturally appropriate and localised NDIS supports for Aboriginal and Torres Strait Islander people with disability.

### **Thin Market Trials**

On 13 December 2019, the Australian Disability Reform Council agreed to use a more flexible approach to addressing the market challenges with NDIS. In addition, the NDIA, key stakeholders, Department of Social Services and territory governments are progressing thin market trials in all states and territories. These trials focus on market intervention approaches to help address issues that are limiting participant access and market growth. The current market trials apply a mix of coordinated funding proposals, market facilitation and direct commissioning.

### **Technology supports**

Accessing internet services can eliminate the need to travel long distances, which saves money and time and potentially increases participant choice of NDIS service providers. Funding for technology supports can be included in a participant's plan if necessary. Internet services are, however, dependent on a reasonable level of "tech saviness", access to the necessary IT equipment and quality internet connectivity – not always achievable in remote locations.

Despite these initiatives to address the challenges in rural, regional and remote Australia, the recent NDIS Review Report acknowledges that, "There is limited access to supports for remote and First Nations participants".<sup>12</sup>

Further, "For all participants living in remote communities who have been in the scheme for at least one year:

- around two in five participants are not getting daily activity supports
- over one in three participants are not getting therapy services."

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<sup>12</sup> Working together to deliver the NDIS, Independent Review into the National Disability Insurance Scheme Final Report, 7 December 2023. <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>, page 186

## How does the NDIS Review Report address rural, regional and remote issues

One of the main ways the NDIS Review Report seeks to address the challenges facing people with disability living in rural, regional and remote locations is through “alternative commissioning approaches”.

The Report states that,

“It is clear community-led and place-based alternative commissioning approaches would improve outcomes for First Nations communities and for all participants in remote communities (see Recommendation 14). A lack of culturally-safe supports often means First Nations participants need to choose between supports that are not culturally safe or not getting supports at all. Drive-in drive-out and fly-in fly-out models in remote communities are not working to communities’ satisfaction.

Alternative commissioning is an opportunity for communities to create their own services. The effective implementation of the NDIS in these communities needs to be built community-by-community.”<sup>13</sup>

Recommendation 14 in the Review Report is to, “Improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements”.

The action associated with this recommendation is, “The National Disability Insurance Agency, in partnership with First Nations representatives, communities, participants and relevant government agencies should progressively roll-out alternative commissioning arrangements for both First Nations communities and remote communities, starting as soon as possible”.<sup>14</sup>

## Core issues affecting the neurological community

The issues, challenges and potential solutions described above affect the entire disability community in rural, regional and remote locations. These issues coupled with the many similar issues in accessing health care supports and services (discussed earlier) are particularly difficult for the neurological community.

These core issues could be summarised as:

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<sup>13</sup> Working together to deliver the NDIS, Independent Review into the National Disability Insurance Scheme Final Report, 7 December 2023. <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>, page 46

<sup>14</sup> Working together to deliver the NDIS, Independent Review into the National Disability Insurance Scheme Final Report, 7 December 2023. <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis>, page 12

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 communities 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 our communities face a range of interlocking issues that potentially undermine service level trust and resilience (e.g. misdiagnosis, delays, working with multiple practitioners simultaneously and remotely, 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 and the resulting functional impairments, refusal of reasonable requests, inconsistent decision making, psychological impacts in part due to not being believed and respected).
5. To date, existing training materials provided to the NDIA 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 within the NDIA where advice and solutions could be developed.

These core issues are exacerbated for those living in rural, regional and remote locations with the added burdens of reduced or no choice of service providers, long waiting times, long and poorly funded travel times, heavy reliance on “telehealth” arrangements which, in turn, rely on good internet connectivity and IT knowledge and equipment. In some cases, it may mean that the participant has to relocate away from their home, family, friends and community to access life-saving services (see Case Study in appendix 1).

## **Solutions and recommendations**

### **Improving NDIS education about neurological/neuromuscular conditions**

Greater awareness, education and understanding within the NDIA of the functional impairments that arise from a diagnosis of a neurological and neuromuscular condition will ensure better support for people living with these conditions that is 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, many have complex and unpredictable needs and others experience a fairly predictable disease course.

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 through a lack of understanding by decision-makers. 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.

Improved awareness, education and understanding must also address issues such as stigma and social exclusion that occur in rural, regional and remote settings.<sup>15</sup>

### **Recommendation 1**

**That the NDIA commits to educating and training staff and contractors about the various functional impairments that arise from being diagnosed with neurological disorders and progressive, degenerative, neurological and neuromuscular conditions including issues of stigma and social exclusion that occur in rural, regional and remote settings.**

### **Recommendation 2**

**That the Government accepts the NDIS Review recommendation for NDIS eligibility to be based on functional impairment (Action 3.1)<sup>16</sup> rather than medical diagnosis and that standardised methods for assessing functional capacity underpin this.**

### **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

<sup>15</sup> Elliot VL, Morgan D, Kosteniuk J, Froehlich Chow A, Bayly M. Health-related stigma of noncommunicable neurological disease in rural adult populations: A scoping review. *Health Soc Care Community*. 2019 Jul;27(4):e158-e188. doi: 10.1111/hsc.12694. Epub 2018 Dec 12. PMID: 30548727; PMCID: PMC6619253.

<sup>16</sup> <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/preface/recommendations-and-actions>

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 to conditions such as the primary progressive form of MS and Machado-Joseph Disease (MJD), 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.

The principles should include special provisions for those living in rural, regional and remote settings that address, for example, access to services and supports, travel and accommodation arrangements, communications needs.

### **Recommendation 3**

**That the NDIA 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) including special provisions for those living in rural, regional and remote locations.**

### **Recommendation 4**

**That the NDIA minimises reassessments where the disease course and level of functional impairment is predictable**

### **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 the likely functional impairments brought about by these conditions that 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 participants with MND or MS, especially those who experience invisible impairments, impairments that come and go, or impairments 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).

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.

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 2021<sup>17</sup> 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.<sup>17</sup>

### **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.

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<sup>17</sup> 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



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.)

## **Recommendation 5**

**That the NDIA 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 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. This is particularly important for those living in rural, regional and remote locations where lack of services and long travel times mean considerable delays in accessing both health and disability services and supports.

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.

## Recommendation 6

**That the NDIA adopts clearer and more timely communications to participants about decision-making processes, timelines and expectations.**

### 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 and recommendations set out in this submission in a constructive, co-operative way.

The cost of individual packages for participants with neurological conditions is comparatively high. The average payment for participants with MS according to the latest participant dashboard for the year ended 30 June 2023<sup>18</sup> is \$93,000 a 16% increase on the previous year and for 'other neurological' primary disability type is \$125,000, a 19% increase on the previous year (with Huntington's disease at \$212,000 and motor neurone disease at \$242,000 as stated in the Participants with a neurodegenerative condition, NDIS Report, 31 March 2021)<sup>19</sup>. This compared, for example, with an average of \$33,800 for Autism plans (a 7% increase on the previous year) and \$16,700 (an 11% increase on the previous year) for developmental delay.

The NDIS Report: Participants with a neurodegenerative condition in the NDIS, March 2021, stated, "Compared with the Scheme overall, the distribution of annualised committed supports is more concentrated at the higher cost bands for participants with a neurodegenerative condition". The poor experiences of participants living with neurological conditions is reflected in the higher number of complaints from this cohort. In March 2021, the rates of complaints were 13% for participants with Muscular Dystrophy and Motor Neurone Disease, 12% for Multiple Sclerosis, 10% for Huntington's Disease and 9% for Parkinson's Disease, compared with the overall Scheme rate of 5%.<sup>20</sup>

The NDIA is currently undertaking a significant reform agenda in response to the Disability Royal Commission, the NDIS Review and other NDIS-related inquiries. The first four recommendations contained in the Report of the recent NDIS inquiry into the Culture and Capability of the NDIA<sup>21</sup> are related to improving the ways "invisible, episodic, rare and psychosocial disabilities" are

<sup>18</sup> <https://data.ndis.gov.au/reports-and-analyses/participant-dashboards>

<sup>19</sup> NDIS Report: Participants with a neurodegenerative condition in the NDIS, March 2021, p44

<sup>20</sup> NDIS Report: Participants with a neurodegenerative condition in the NDIS, March 2021, p24

<sup>21</sup> [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/CapabilityandCulture/Report](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/CapabilityandCulture/Report)

regarded and assessed by the NDIA. The NAA welcomes a focus on those disabilities brought about by neurological conditions. Many of these invisible, episodic, rare and psychosocial disabilities are experienced by the communities served by the NAA member organisations.

The major NDIS Review Report was recently handed down by the Minister for the NDIS, the Hon Bill Shorten MP. It contains 26 recommendations plus a large number of actions under each recommendation requiring implementation. The NAA believes it is in the best position to be able to assist the Federal Government to implement these recommendations and actions as they relate to the neurological community and would provide additional advice and solutions for those living in rural, regional and remote locations. A Neurological Working Group would assist the NDIA with the implementation of the recommendations of each of these major NDIS-related reviews and inquiries.

## **Recommendation 7**

### **That the NDIA establish a Neurological Working 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 NDIS participant experience in rural, regional and remote Australia. 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 in rural, regional and remote locations.

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## Appendix 1 Case study:

### ABC News Report sourced through Developing Australian Communities<sup>22</sup>:

#### **“Paulette didn't want to leave her remote community, but a lack of NDIS support services meant she had no choice”**

More than 1700 NDIS participants live in remote parts of the Northern Territory, but advocates say many like Paulette Bumarda struggle to access adequate support, forcing them to relocate to the city, the ABC reported.

Paulette didn't want to leave her remote community, but a lack of NDIS support services meant she had no choice.

Her story highlights the dire need for more services and more support for participants in the bush.

Paulette was forced to leave her community and family at her remote Northern Territory home and move to Darwin. While she is very homesick, Paulette agrees the move was essential for her health.

She has Machado-Joseph's disease, a rare neuro degenerative condition that occurs because of a fault in a chromosome that results in the production of an abnormal protein.

This protein causes nerve cells to die prematurely in a part of the brain called the cerebellum. This damage initially causes muscular weakness and progresses over time to a total lack of voluntary control and very significant permanent physical disability.

In Darwin, Paulette can access a range of supports under her NDIS plan that she simply could not in her home community because nothing was available there.

Her care plan includes specialist accommodation and multiple weekly physiotherapy sessions.

But she had to leave her home to access this help.

Paulette is not alone. There are people with disabilities throughout rural Australia that are either forced to leave their homes and move to major centres or cities to access vital NDIS services and support, or drive hundreds of kilometres regularly to do so.

Or they simply stay where they are and make do with little or no suitable support because they can't access adequate care for their needs because there just are not enough providers.

There are just more than 9200 NDIS service providers across the nation, but Australia's peak disability advocacy group says lack of suitable staff accommodation and inadequate pricing levels provide major hurdles in getting those providers to these remote locations.

Nadia Lindop, from National Disability Services (NDS) NT, told the ABC that even though there is a 25% loading on prices for remote services, it doesn't really reflect the real cost of doing business in remote communities.

NDIS participant Jason Motbey shares a similar story. He also had to leave his rural community and move to Darwin to access support and services to help manage his spinal condition.

*“The reality is, the more I stayed out there (at his home community) the more my health declined,”* he said.

<sup>22</sup> <https://www.abc.net.au/news/2021-12-05/paulette-didnt-want-to-leave-her-remote-community-ndis-support/13662870?fbclid=IwAR2xLxI9EOx8ManncHIKUh9PXoESGD2kK8M9AKzA-2-ym-l3bWgJapsxoE>