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# Submission to the Department of Social Services consultation on Foundational Supports

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November 2024

**Rohan Greenland**  
**Chair**

**Anne Wilson**  
**Deputy Chair**

***The Neurological Alliance Australia** is an alliance of 35 not-for-profit peak 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.*

- *Overseas studies indicate as many as 1 in 3 people live with a neurological condition, the leading cause of illness and disability worldwide<sup>1</sup>*
- *We estimate that 1 in 4 Australians live with neurological or neuro-muscular conditions, or neurological disorders, with an annual impact on the Australian economy of over \$100 billion<sup>2</sup>*
- *These conditions represent around 14% of NDIS participants<sup>3</sup>*
- *According to the AIHW Australian Burden of Disease Study 2023, neurological conditions are one of the five leading disease groups causing burden in 2023<sup>4</sup>*
- *To read more about the work of the Alliance, its members and our six pressing areas of need, please visit: <https://neurologicalalliance.org.au/count-us-in/>*

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<sup>1</sup>Retrieved from: <https://www.who.int/news/item/14-03-2024-over-1-in-3-people-affected-by-neurological-conditions--the-leading-cause-of-illness-and-disability-worldwide>

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

<sup>3</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>

<sup>4</sup> Retrieved from Australian Burden of Disease Study 2023, About - Australian Institute of Health and Welfare ([aihw.gov.au](http://aihw.gov.au))

## Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a submission to the Department of Social Services consultation on Foundational Supports.

Neurological and neuromuscular conditions and disorders have a devastating impact on those diagnosed, their families, friends and loved ones.

These conditions are on the rise in Australia and worldwide, yet despite being recognised as one of the nation's top disease burdens, neurological conditions remain under-recognised and underfunded.

The urgent unmet needs for people living with neurological and neuromuscular disorders and conditions in Australia are:

- Better treatments, prevention and ultimately, cures for these diseases - cures could well be within reach.
- Improved support for the management and care of people affected by neurological and neuromuscular conditions and disorders - through systemic improvements to the health care, disability care and aged care sectors.

This submission focusses on several key Foundational Supports that will have a positive impact on people living with neurological and neuromuscular conditions and disorders.

## Summary of recommendations:

### Recommendation 1

Organisations with long-standing specialist expertise in neurological and neuromuscular conditions and neurological disorders should be encouraged and incentivised to build on existing foundational support offerings.

### Recommendation 2

Organisations with well-established expertise in creating and maintaining peer support networks for people living with neurological and neuromuscular conditions and disorders, should be encouraged and incentivised to increase engagement with their communities and expand these existing networks.

### Recommendation 3

That the role of Neurological Navigator be added to the suite of Navigators providing specialist knowledge of the particular needs of people living with neurological and neuromuscular conditions and disorders and connection to relevant specialist services and support.

### Recommendation 4

That harmonised and unified national Assistive Technology access be established to meet the needs of people with disability who do not qualify for the NDIS.

## General foundational supports

General foundational supports are described by the NDIS Review Panel as those that include programs and activities like information and advice, individual and family capacity building, peer support, self-advocacy, and disability employment supports.<sup>5</sup>

Most, if not all, of the members of the NAA have been providing general foundational supports for the conditions they represent for many, many years. They have built considerable expertise in tailoring services and supports to the communities they serve. In the main these supports are not funded through government grants, but through fund-raising activities, bequests and donations. In some cases, especially where these organisations represent conditions with relatively smaller and rare cohorts, the capacity to provide “general supports” is limited.

People living with neurological and neuromuscular conditions often tell us they want services, support and information from the peak organisation that represents them – a “one stop shop” – so they do not have to repeatedly explain their symptoms and disease course over and over again.

Organisations with long-standing specialist expertise in the neurological and neuromuscular conditions and disorders they represent should be encouraged and incentivised to increase engagement with their communities and build on existing foundational support offerings.

### Recommendation 1

**Organisations with long-standing specialist expertise in neurological and neuromuscular conditions and neurological disorders should be encouraged and incentivised to build on existing foundational support offerings.**

## Peer support networks

“The experience [of joining an MS peer support group] was life-changing for me. Not only did I receive great and relevant information and education about MS, but I was also no longer isolated and alone.”<sup>6</sup>

Many people living with neurological and neuromuscular conditions and disorders report the enormous benefits of involvement in peer support groups.

A growing bank of evidence supports this.<sup>7,8,9</sup>

Peer support networks are now able to meet in a variety of formats online, face-to-face, in groups and one-to-one. They cater to a diverse range of interests and

<sup>5</sup> [Foundational supports for all people with disability | NDIS Review](#)

<sup>6</sup> <https://www.msplus.org.au/support-services/connecting-with-your-community/peer-support>

<sup>7</sup> <https://aci.health.nsw.gov.au/projects/consumer-enablement/how-to-support-enablement/peer-support>

<sup>8</sup> <https://www.ipfcc.org/bestpractices/global-evidence-for-peer-support.pdf>

<sup>9</sup> <https://pmc.ncbi.nlm.nih.gov/articles/PMC10038377/>

activities, with the commonality of a shared diagnosis of a neurological or neuromuscular condition or as a carer for someone with such a condition. Often peer support networks are convened and managed by people with lived experience of these conditions, building trusted communities of support, shared experience and information.

## Recommendation 2

**Organisations with well-established expertise in creating and maintaining peer support networks for people living with neurological and neuromuscular conditions and disorders, should be encouraged and incentivised to increase engagement with their communities and expand these existing networks.**

## Neurological Navigators

The NDIS Review Panel has a stated vision for, “a connected system of support for people with disability. This connected system should include accessible and inclusive mainstream services, foundational supports and individual support funded through the NDIS. We also want all people with disability and their families to have more help to navigate this system”.<sup>10</sup>

They have recommend creating a new role called a Navigator.

In summary, a Navigator should:

- have good local knowledge to support people with disability and their families to understand, find and use mainstream and community services, as well as foundational supports.
- help participants find, use and pay for NDIS funded services from their budgets, similar to the role of support coordinators currently.
- be directed by people with disability, and act in their interests.

The role is intended to help both NDIS participants and those with disability not in the NDIS.

In the NDIS Fact Sheet regarding the role of navigators, six types of navigator are described:

- General navigator,
- Specialist navigator,
- Psychosocial recovery navigator,
- Housing and living navigator,
- Shared support facilitator and
- Lead practitioner.

The NAA supports the creation of these roles and recommends the addition of a Neurological Navigator. The Neurological Navigator would have specialist knowledge of the particular needs of people living with neurological and

<sup>10</sup> <https://www.ndisreview.gov.au/resources/fact-sheet/finding-your-way-around-help-navigator>

neuromuscular conditions and disorders, the way these conditions progress, in some cases their episodic nature, and connect people living with these conditions with relevant specialist services and support. The Neurological Navigator would provide navigation to both NDIS participants and those outside the NDIS.

The neurological and neuromuscular conditions represented by the members of the NAA have no cures, only a few have affordable disease-modifying treatments via the Pharmaceutical Benefits Scheme, some have a rapid, degenerative trajectory. A diagnosis is devastating for the person diagnosed, their family, friends and loved ones.

The role of the Neurological Navigator is vital for those newly diagnosed who are coping with the emotional and physical impact of their diagnosis, find the information landscape confusing and often do not know where to turn for information, services and support. At any point in time a person diagnosed with a neurological or neuromuscular condition may need to access the health, disability and/or aged care systems which can be siloed and complex. In many cases, the speed of diagnosis, initiating treatment plans, adopting a brain healthy lifestyle and obtaining specialist services and support is vital for slowing the progress of disability associated with these conditions.

The 1 in 4 Australians who live with a neurological or neuro-muscular condition or a neurological disorder, including an estimated 14% of NDIS participants have the potential to benefit from access to a Neurological Navigator.

### **Recommendation 3**

**That the role of Neurological Navigator be added to the suite of Navigators providing specialist knowledge of the particular needs of people living with neurological and neuromuscular conditions and disorders and connection to relevant specialist services and support**

#### **4. Establish harmonised and unified national Assistive Technology access to meet the needs of people with disability who do not qualify for the NDIS.**

Assistive technology (AT) plays a critical role in the lives of people with disability of all ages by facilitating independence and participation in everyday activities.

The NDIS is able to provide scheme participants with fully funded access to assistive technology, but the situation for those who are excluded from the scheme is very different. Older people with disability bear the brunt of this arrangement, as the age cut-off for eligibility for the NDIS is 65.

People with disability who are excluded from the NDIS are commonly required to wait well over a year to access funding for AT. They are forced to self-fund part or all of the equipment they need, often at considerable expense and in some cases, they simply go without.

Provision of AT keeps people living their lives better – in work and at home, resulting in less demand on support systems within the health, disability and aged care sectors.

A study commissioned by Council on the Ageing Victoria<sup>11</sup> titled “*Establishing and costing a single national assistive technology and home modifications program to support people with disability who are not eligible for the NDIS*”<sup>12</sup> demonstrated that current levels of unmet need would best be resolved through the establishment of a single national assistive technology and home modifications program.

A single national assistive technology and home modifications funding program will support all people with disability who are ineligible for the NDIS, irrespective of age. A single national funding model will enable existing successful organisations that implement AT models to continue operating but access funding from one national pool of funds.

#### Key findings of the study

#### **Two out of three older people with disability who are not eligible for the NDIS access support from the aged care system.**

Currently the average spend on assistive technology and home modifications per person per year for NDIS participants is \$2,500, compared with just \$51 per person per year for aged care recipients.

#### **Current schemes for providing assistive technology and home modifications (AT/HM) are fragmented and complex**

109 separate AT/HM schemes were identified in the study.

#### **Lack of equity across state/territory boundaries**

Each state/territory has a flagship AT/HM Scheme. All have different eligibility criteria, different AT/HM in scope and different rationing methods e.g. subsidy rates.

#### **Return on government investment**

An annual investment of \$16 billion could ultimately save \$32 billion. For every dollar spent on assistive technology and home modifications, there is a conservative estimated two-fold return on investment relating to savings on the cost of paid carers, support and medical services. The timely provision of assistive technology and home modifications can also prevent or delay entry to residential care, the cost benefits of which are not included in this estimate.

<sup>11</sup> Council on the Ageing (COTA) Victoria lead the Assistive Technology for All (ATFA) alliance of 65 peak organisations that have joined forces to advocate for a single assistive technology program to meet the needs of people with disability who are excluded from the NDIS. To read more, please visit:

<https://assistivetechforall.org.au>

<sup>12</sup> Layton, N., & Brusco, N. (2022). *The Australian assistive technology equity studies: Improving access to assistive technology for people with disability who are not eligible for the NDIS*. Monash University; COTA Victoria. <https://doi.org/10.26180/21113887>

Data in the study suggests that for every \$1.00 spent on high level assistive technology and/or home modifications, up to an additional \$1.98 is spent on organisational/administrative costs. Consolidating the 109 existing funding streams into one national program could create further cost efficiencies for Government by reducing the administrative burden associated with operating the existing multiple schemes.

### **Assistive technology in the new Support at Home Program**

The new Support at Home program<sup>13</sup>, to be implemented from 1 July 2025, includes an Assistive Technology and Home Modifications (AT-HM) Scheme, designed to give participants access to assistive technology and/or home modifications without needing to save up funds from their individual budgets. It is suggested funding will cover prescription from allied health professionals, when required, with wraparound supports to ensure the item is used safely and effectively, though a detailed list of items the Scheme will cover is not yet available.

The Scheme has also been designed to include the ability for older people with progressive conditions to easily swap equipment as their condition progresses.

Hopefully this new Scheme will go some way to address the inequities in the provision of assistive technology for those aged over 65 outside the NDIS, though capping and means testing of the scheme means inequities will remain.

#### **Recommendation 4**

**That harmonised and unified national Assistive Technology access be established to meet the needs of people with disability who do not qualify for the NDIS.**

For more information about this submission and the work of the Neurological Alliance Australia please contact:

Andrew Giles  
Executive Officer  
Email: [Andrew.giles@neurologicalalliance.org.au](mailto:Andrew.giles@neurologicalalliance.org.au)

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<sup>13</sup> <https://www.health.gov.au/our-work/support-at-home/features>