
Submission to the Department of Health and Aged Care consultation on the new Aged Care Act

8 March 2024

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***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.*

***The Neurological Alliance Australia** represents the approximately 1 in 6 Australians¹ living with neurological or neuromuscular conditions or neurological disorders with an annual impact on the Australian economy of over \$100 billion².*

¹ 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>

² Based on an aggregation of data from organisations who have commissioned economic impact studies

Summary of recommendations

The Neurological Alliance Australia (NAA) recommends that:

1. **Supports for people with disability aged over 65 years be made an explicit reason to access the aged care system in the Eligibility for Entry section of the Act.**
2. **The new Act must clearly articulate those mechanisms that will ensure older people with disability will receive appropriate supports and services equivalent to the NDIS.**
3. **The use of computer-based decision-making tools should:**
 - **include the disability needs of those accessing aged care, focus on reablement and rehabilitation and involve supplementary assessments by allied health experts**
 - **include regulatory safeguards and be monitored and audited, with the findings of the audit included in annual reports on the operations of the system.**
4. **The role of informal, unpaid carers and their importance to older people, as well as their needs, should be reflected in the relevant sections of the Act including equitable and timely access to respite and other available supports.**
5. **The findings and recommendations of the Aged Care Taskforce that are to be adopted into the exposure draft of the new Aged Care Act be published as soon as possible.**

About neurological disorders and progressive neurological and neuromuscular conditions

The NAA is pleased to provide this submission to the Department of Health and Aged Care consultation on the new Aged Care Act.

The focus of the comments provided in this submission are on key areas of the new Act 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.

These conditions represent around 14% of NDIS participants³.

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

³ Based on an aggregation of neurological 'primary disability groups' in the NDIS quarterly reports <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

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, many 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.

Introduction

The NAA supports the overall intention of introducing a new “rights-based” Aged Care Act by creating a simplified, rights-based legislative framework, with one piece of primary legislation that regulates aged care.

The new aged care Act has been designed to focus on the safety, health and wellbeing of older people and put their needs and preferences first through measures that include:

- Embedding a rights-based approach by introducing a Statement of Rights, complying with international conventions, introducing independent system oversight and allowing for equitable access through a single assessment framework
- Empowering individuals through revised nominee arrangements, increased system transparency, a new complaints management framework and support and funding for aged care advocacy
- Enforcing obligations on aged care providers and the aged care workforce
- Introducing a Statement of Principles to guide decisions, actions and behaviours required under the new Act, a legal framework to improve supported decision making and increased protection for whistleblowers.

Areas of concern

A number of aged care advocacy organisations, including the NAA and its members, have raised concerns about gaps in the new Act including the lack of recognition of the disability needs of older Australians, funding inequities between aged care and the NDIS, the use of computer programs to make decisions, the lack of recognition of the role of informal, unpaid carers and the

lack of information about the findings and recommendations of the Aged Care Taskforce that are to be adopted into the new Act.

Lack of recognition of the needs of older Australians with disability

The Act should recognise that older people are seeking to access the aged care system for disability supports.

Currently, all people who acquire a disability on or after the age of 65 years must obtain support for their disability from the aged care system. Permanent disability does not disappear once someone turns 65 (and is classified as 'aged'). A person's care needs as a result of neurodegenerative disability add another dimension of complexity, as opposed to standard care for someone who is aged and without a disability.

Accordingly, the Act should recognise the reasons why older people with a disability are seeking services from aged care to improve or maintain their functions. improve their quality of life and maintain their independence.

Recommendation

Make supports for people with disability aged over 65 years an explicit reason to access the aged care system in the Eligibility for Entry section of the Act.

Funding inequities between aged care and the NDIS

The new Act does not address the levels of inequity between aged care packages and the NDIS. Currently aged care packages are grossly inadequate for older people with disabilities such as those resulting from the conditions represented by the NAA.

An older person with disability may only get a package to a maximum of \$60,000, which means extremely limited supports.

The cost of individual NDIS 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 2023⁴ 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)⁵.

⁴ <https://data.ndis.gov.au/reports-and-analyses/participant-dashboards>

⁵ NDIS Report: Participants with a neurodegenerative condition in the NDIS, March 2021, p44

The Aged Care Royal Commission final report stated clearly that: “Older Australians with a disability should receive, through the aged-care system, daily supports and assistive technology equivalent to the NDIS”.⁶

Many Australians who live with neurological conditions are over the age of 65 when diagnosed or when their level of disability requires supports and services. This means they are not eligible to access these supports and services from the NDIS.

Section 22 (11) of the proposed Act says:

“The Commonwealth aged care system focusses on the needs of older people, and should not be used inappropriately to address service gaps in other care and support sectors”.⁷

The NDIS Independent Review final report states:

“For people with disability aged over 65, foundational supports will need to work effectively with services and supports provided through the aged care system”.⁸

There is a clear disconnect between what is stated in the proposed Act and the directive from the NDIS Independent Review.

Recommendation

The new Act must clearly articulate those mechanisms that will ensure older people with disability will receive appropriate supports and services equivalent to the NDIS.

Use of computer programs to make decisions

The new Act (under Part 7) refers to powers of the System Governor that allow for the use of a computer program to automatically determine decisions relating to the classification of individuals and for prioritisation of accessing aged care.

The focus of classification and prioritisation should not be solely on ageing. The decision-making algorithms should consider the disability needs of those accessing aged care. This is of particular concern for assessing those with complex needs requiring specialised disability support, such as assistive technology, with a focus on reablement and rehabilitation rather than frailty. Supplementary assessments involving allied health professionals with expertise in neurological and/or neuromuscular conditions and disorders should be considered.

⁶ <https://www.royalcommission.gov.au/aged-care/final-report>

⁷ <https://www.health.gov.au/our-work/aged-care-act/consultation>

⁸ NDIS independent Review, Chapter One.

It is necessary with any use of artificial intelligence that the system includes measures to build transparency and confidence. Regulatory safeguards, audits and reporting of the use of computers to make decisions on behalf of the System Governor are needed.

The Australian Human Rights Commission in its submission to the Department of Industry, Science and Resources discussion paper on responsible AI, titled, “The Need for Human Rights-centred Artificial Intelligence”, July 2023, made the following observations:

- “AI [artificial intelligence] allows large amounts of relevant information to be considered in decision-making processes, enabling ‘efficient’ decision making. However, regulation is increasingly important due to an algorithm’s potential to produce ‘algorithmic bias’. Algorithmic bias arises where an ADM [automated decision-making] tool produces outputs that result in unfairness. Algorithmic bias can entrench unfairness, or even result in unlawful discrimination.
- AI and ADM require greater regulation, in the interests of increasing transparency, preventing unfairness and unlawful discrimination in algorithmic decision-making.
- Australia must do more to regulate the use of AI and ADM as a matter of priority, most notably in cases where the decisions made have a legal, or similarly significant, effect for individuals.”⁹

Regulatory safeguards for the use of AI systems including auditing and monitoring, should be included in the new Act.

Recommendation

The use of computer-based decision-making tools should:

- **include the disability needs of those accessing aged care, focus on reablement and rehabilitation and involve supplementary assessments by allied health experts**
- **include regulatory safeguards and be monitored and audited, with the findings of the audit included in annual reports on the operations of the system.**

Inadequate recognition of the role of informal, unpaid carers

The Aged Care Royal Commission made several recommendations to address the needs of informal, unpaid carers of people receiving aged care, including the need to provide respite (recommendation 1) and certainty that they will receive timely and high quality supports in accordance with assessed need (recommendation 2).¹⁰

⁹ <https://humanrights.gov.au/our-work/legal/submission/need-human-rights-centred-ai>

¹⁰ <https://www.royalcommission.gov.au/aged-care/final-report>

Whilst the role of informal carers is recognised in the new Act, the role and needs of carers in supporting older people who receive aged care services, as envisaged by the Aged Care Royal Commission recommendations, must be responded to or addressed.

Recommendation

The role of informal, unpaid carers and their importance to older people, as well as their needs, should be reflected in the relevant sections of the Act including equitable and timely access to respite and other available supports.

Public release of the findings and recommendations of the Aged Care Task Force

An Aged Care Task Force was established by the Federal Government in June 2023, as a “a time-limited body to provide expert advice to government through the Minister for Aged Care”.¹¹

The Taskforce was due to report in December 2023 on the future financing and funding of aged care, yet its findings and recommendations are yet to be released. Also yet to be made public are those Taskforce findings and recommendations that are to be adopted into the exposure draft of the new Aged Care Act.

Recommendation

That the findings and recommendations of the Aged Care Taskforce that are to be adopted into the exposure draft of the new Aged Care Act be published as soon as possible.

¹¹ <https://www.health.gov.au/committees-and-groups/aged-care-taskforce>