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# New Aged Care Act: Exposure Draft

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# SUBMISSION



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# New Aged Care Act: Exposure Draft

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MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS.

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

# New Aged Care Act: Exposure Draft

MS Australia welcomes the development of a new Aged Care Act to better meet the needs of older Australians and improve the delivery of aged care services. We welcome the new person-centered Act and the focus on the rights and needs of older people. This submission and MS Australia's feedback focuses on Older Australians with disability.

## MS Australia Recommendations

- Updating the new Aged Care Act to incorporate more references to disability including disability awareness, supporting the needs of people with disability and meeting the obligations of the Convention on the Rights of Persons with Disabilities.
- Stronger links in the new Aged Care Act between the aged care system and the NDIS to support people who may access supports from both systems.
- Replace sections (j) to (l) of the Note under Section 22(4) with 'are a person with disability'.
- Include a definition of 'disability' in Section 7 which aligns with the definition used in the Convention on the Rights of Persons with Disabilities.
- Update section 22(4) to include awareness of intersectionality for people from special needs groups and the compounding impacts.
- Update the definition of the Convention on the Rights of Persons with Disabilities in Section 7 to read 'Convention on the Rights of Persons with Disabilities means the 27 Convention on the Rights of Persons with Disabilities adopted at New York on 13 December 2006'.

## Older People with Disability

People living with disability make up a large proportion of the Australian community with 1.9 million Australians aged 65 years and over living with disability. This means 50% of people aged 65 and over have a disability and this represents almost half (44.5%) of all Australians with disability<sup>1,2</sup>. As such they represent a significant proportion of aged care recipients.

Currently, Australians living with MS aged 65 and over when the NDIS was introduced and those who develop a disability and/or first access services after turning 65 are ineligible for the NDIS and must either self-fund their care or pursue their disability needs through the aged care system. However, the current aged care system does not cater to the needs of older Australians living with fluctuating or episodic disability or health conditions. Aged care services do not meet the disability specific needs of people living with MS, including providing appropriate assistive technology, specialised care, allied health and therapy services and supported independent living. Older people living with MS must either self-fund the shortfall in aged care services or go without, causing greater decline in their health and disability and leading to increased hospitalisation and greater long-term burden on the health and disability systems.

The Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission) found that older people with disability receiving aged care do not have access to services and supports at the same level as those provided to people through the NDIS. The Aged Care Royal Commission recommended the new aged care system include equity for people with disability (recommendation 72):

*By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions<sup>3</sup>.*

Despite this recommendation from the Aged Care Royal Commission, to date there is very little reference in the aged care reform agenda to meeting the needs of older people with disability. It is crucial that this Royal Commission recommendation is considered as part of the reforms.

MS Australia acknowledges that the new Aged Care Act includes two specific sections relating to people with disability:

- Section 5a under the Objects of the Act that gives effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities (CRPD)
- The Note under Section 22(4) listing individuals who may need accessible, culturally safe, culturally appropriate, trauma-aware and healing-informed care.

However, these are the only two mentions and there are no other linkages within the Act to the CRPD. The current draft Act represents people with disability as being more like a 'special needs' group. People with disability are a significant and substantial group of people accessing aged care and they need more than consideration in diversity plans. They need access to tangible disability supports and services, disability aware staff and providers, disability inclusive assessments and a complaints and safeguarding system that understands disability.

**MS Australia** recommends updating the new Aged Care Act to incorporate more references to disability including disability awareness, supporting the needs of people with disability and meeting the obligations of the CRPD.

## Interaction with the NDIS

MS Australia has long advocated that older people living with MS should have access to NDIS supports to meet their disability needs. As such, MS Australia welcomes the following recommendation by the NDIS Review:

*The Australian Government should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary (Action 2.11, NDIS Review Final Report).*

The Final Report also notes that 'People aged over 65 will likely benefit from foundational supports, but should receive most of their supports from the aged care system'. They should be able to access the supports they need from the most appropriate system including disability appropriate supports from the NDIS and ageing supports from the aged care system. Additionally, for those entering residential aged care they will be able to access complementary NDIS supports as needed.

In light of this, it is critical that the aged care system can meet the needs of people with disability and also interact with the National Disability Scheme (NDIS). Older people with disability should be able to navigate both the aged care system and the NDIS seamlessly. Staff providing navigation support including My Aged Care and Care Finders and the assessment workforce should have a basic understanding of the NDIS and which systems people with disability should be accessing supports from. Providers should have an understanding of the NDIS so they can support their clients to access supports and services and know which system best meets their needs.

**MS Australia recommends** stronger links in the new Aged Care Act between the aged care system and the NDIS to support people who may access supports from both systems.

## Statement of Principles

MS Australia supports the inclusion of a Statement of Principles in the new Aged Care Act and the inclusion of specific groups under Section 22(4). However, the list of disability specific groups in the Note under this section is inconsistent and does not use best practice disability language as follows:

- (j) individual with disability – best practice terminology in the disability space is 'person with disability'.
- (j)mental ill-health – this is not a commonly used term and is best replaced by 'person living with a mental health condition'. However, given this is a sub-set of disability it can just be covered by 'person with disability'.
- (k) neurodivergent – this is not a medical term and there is no firm agreement on the definition and on what disorders and conditions it covers. This term is also not exclusively accepted across the disability sector.

- (l) deaf, deafblind, vision impaired or hard of hearing – there is no clear reason why only this specific disability group would be included and not others.

To ensure equity this Note should refer to all people with a disability and not to only a few specific disability groups.

**MS Australia recommends** replacing sections (j) to (l) of the Note under Section 22(4) with 'are a person with disability'. This can be accompanied by a clear definition in Section 7 (see below).

Many people living with disability intersect with a range of other diverse needs groups including Aboriginal and Torres Strait Islander people, LGBTQI+ people, people who are homeless or at risk of homelessness and people who are financially and socially disadvantaged. Aged Care providers should be aware that their clients may belong to multiple social and cultural groups and be aware of any compounding impacts. Understanding and embracing intersectionality will lead to a more inclusive and compassionate aged care system.

**MS Australia recommends** updating section 22(4) to include awareness of intersectionality for people from diverse groups and the compounding impacts.

## Definitions

**MS Australia recommends** including a definition of 'disability' in Section 7 which aligns with the definition used in the Convention on the Rights of Persons with Disabilities (CRPD):

*'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'* Article 1, CRPD<sup>4</sup>

**MS Australia recommends** updating the definition of the CRPD in Section 7 from 'Convention on the Rights of Persons with Disabilities means the 27 Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006' to 'Convention on the Rights of Persons with Disabilities means the 27 Convention on the Rights of Persons with Disabilities adopted at New York on 13 December 2006'.

## Reference

- <sup>1</sup> Australian Bureau of Statistics. (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. ABS. Retrieved from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
- <sup>2</sup> Australian Institute of Health and Welfare (2022) *People with disability in Australia 2022*, catalogue number DIS 72, AIHW, Australian Government.
- <sup>3</sup> Royal Commission into Aged Care Quality and Safety (2021). *Final Report: Care, Dignity and Respect (Volume 1)*. Retrieved from: <https://agedcare.royalcommission.gov.au/publications/final-report>
- <sup>4</sup> *United Nations Convention on the Rights of Persons with Disabilities*, December 13, 2006, <https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx>

