

Ensuring the New Aged Care Act Reflects the Rights, Needs and Interests of Older People with Disability

Submission to the Commonwealth Department of Health and Aged Care

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About AFDO

Since 2003, the Australian Federation of Disability Organisations (AFDO), a Disabled Peoples Organisation (DPO), a funded Disability Representative Organisation (DRO), has been the recognised national peak organisation in the disability sector, along with its disability specific members, representing people with disability. AFDO's mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life.

Our thirty-five (35) member organisations represent disability specific communities and cross-disability communities with a total reach of over 4 million Australians.

AFDO continues to provide a strong, trusted, independent voice for the disability sector on national policy, inquiries, submissions, systemic advocacy and advisory on government initiatives with the Federal and State/Territory governments.

We work to develop a community where people with disability can participate in all aspects of social, economic, political and cultural life. This includes genuine participation in mainstream community life, the development of respectful and valued relationships, social and economic participation, and the opportunity to contribute as valued citizens.

Our vision

That all people with disabilities must be involved equally in all aspects of social, economic, political and cultural life.

Our mission

Using the strength of our membership-based organisations to harness the collective power of uniting people with disability to change society into a community where everyone is equal.

Our strategic objectives

To represent the interests and united voice of our members and people with disability at a national and international level in all relevant forums.

To build the capacity, profile, reputation and sustainability of AFDO through the strength of our member organisations.

To enhance the connection and influence in international disability initiatives by policy, advocacy and engagement, focused on the Asia Pacific region.

Our members

Full members:

- Advocacy for Inclusion Incorporated
- Arts Access Australia
- Autism Aspergers Advocacy Australia
- Blind Citizens Australia
- Brain Injury Australia
- Deaf Australia
- Deafblind Australia
- Deafness Forum Australia
- Disability Advocacy Network Australia
- Disability Justice Australia
- Disability Resources Centre
- Down Syndrome Australia
- Enhanced Lifestyles
- National Mental Health Consumer & Carer Forum
- People With Disabilities WA
- Polio Australia
- Physical Disability Australia
- South West Autism Network WA
- Women With Disabilities ACT ACT
- Women with Disabilities Victoria Vic

Associate members:

- Advocacy WA
- All Means All
- AED Legal Centre
- Amaze Vic
- Aspergers Victoria
- Disability Voices Tasmania
- Disability Advocacy and Complaints Service of South Australia
- Explorability Inc
- Leadership Plus
- Multiple Sclerosis Australia
- National Organisation for Fetal Alcohol Spectrum Disorder
- National Union of Students Disabilities Department
- Star Victoria Inc
- TASC National Limited
- Youth Disability Advocacy Service











































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Acknowledgements

AFDO acknowledges Aboriginal and Torres Strait Islander people as the traditional custodians of the land on which we stand, recognising their continuing connection to land, waters, and community. From our offices in Melbourne, Canberra, Sydney and Brisbane, we pay our respects to the peoples of the lands on which these operate and to their respective Elders past, present, and emerging. We also pay our respects to the traditional owners of all lands on which we operate or meet around the country.

AFDO acknowledges people with disability, particularly those individuals that have experienced or are continuing to experience violence, abuse, neglect, and exploitation. We also acknowledge their families, supporters, and representative organisations and express our thanks for the continuing work we all do in their support.

AFDO would like to acknowledge the National Assistive Technology Alliance (NATA), of which AFDO is a participating member, for its submission responding to the Commonwealth Department of Health Report on "a new Assistive Technology and Home Modifications Program for In-home Care" which has been utilised to support our submission to the Review Panel.

AFDO would like to thank our colleagues at the Older Persons Advocacy Network (OPAN), whom we recently partnered with to author a joint discussion paper on access to supports for older people with disability which has contributed significantly to this submission.

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Introduction

We thank the Department of Health and Aged Care for providing us with an opportunity to inform the development of the new Commonwealth Aged Care Act. This submission will focus on the extent to which the consultation paper reflects the rights, needs and interests of older Australians with disability. Due to time constraints, we have chosen not to comment on every aspect of the consultation paper. Instead, we have highlighted some key areas we would like to see strengthened and improved in the exposure draft.

We would like to acknowledge and thank members of the National Assistive Technology Alliance (NATA), whom we worked with earlier this year to prepare a joint submission on the Department's proposed framework for a new assistive technology and home modifications program for in-home care. We have drawn extensively on this work to inform this submission.

We would also like to thank our colleagues at the Older Persons Advocacy Network (OPAN), whom we recently partnered with to author a joint discussion paper on access to supports for older people with disability. We have drawn on this discussion paper extensively to inform this submission and by ultimately publishing this paper, we hope to:

- Educate governments, service providers and advocacy organisations on key issues and statistics relating to ageing with a disability or obtaining a disability later in life.
- Promote the rights and needs of people ageing with a disability or who acquire a disability later in life.
- Improve the quality of the discussion around meeting the needs of older people with disability through the current aged care reforms, and other federal, state and territory programs.

We were still in the process of finalising the discussion paper at the time of writing this submission but would be happy to provide a draft copy to the Department upon request.

Summary of recommendations

- 1. The new Act must give rise to:
 - Obligations outlined under the Convention on the Rights of Persons with Disabilities
 - Obligations outlined under Australia's Disability Strategy 2021-31, and
 - Recommendation 72 from the Royal Commission into Aged Care Quality and Safety.
- 2. The objects of the new Act must reference the United Nations Principles for Older Persons and achieve greater alignment with the objectives outlined under Section 3 of the National Disability Insurance Scheme Act (Cth) 2013.
- 3. The purpose of the new Act should be:
 - To support older people to remain active and engaged members of their community, irrespective of their age or level of physical, sensory or cognitive capability
 - To support older people to remain living in their own homes for as long as possible.
- 4. The statement of rights must be revised to achieve greater alignment with relevant Articles of the Convention on the Rights of Persons with Disabilities, namely:
 - Article 5 Equality and non-discrimination
 - Article 6 Women with disabilities
 - Article 9 Accessibility
 - Article 10 Right to life
 - Article 11 Situations of risk and humanitarian emergencies
 - Article 12 Equal recognition before the law
 - Article 14 Liberty and security of the person
 - Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment
 - Article 16 Freedom from exploitation, violence and abuse
 - Article 17 Protecting the integrity of the person
 - Article 19 Living independently and being included in the community
 - Article 20 Personal mobility
 - Article 21 Freedom of expression and opinion, and access to information
 - Article 22 Respect for privacy
 - Article 25 Health
 - Article 26 Habilitation and rehabilitation

- Article 28 Adequate standard of living and social protection
- Article 29 Participation in political and public life
- Article 30 Participation in cultural life, recreation, leisure, and sport
- 5. Older people with permanent and severe disability who do not meet the age eligibility requirements for the NDIS must be explicitly referenced underneath principle 7 of the Act.
- 6. The Department of Health and Aged Care must liaise with the Disability Reform Ministerial Council and the Department of Social Services to determine a best practice approach to providing timely and equitable access to specialist disability services and supports across service systems. The new Act must not prevent older people with permanent and severe disability from accessing supports from multiple service systems depending on their individual needs and circumstances.
- 7. The Department must adhere to Recommendation 125 from the Royal Commission into Aged Care Quality and Safety as it works with stakeholders to develop a funding model for the new aged care Act, noting its obligation to ensure older people with disability are able to access supports on an equitable basis with participants of the NDIS.
- 8. The new Act must include an additional principle relating to timely access to support, noting that the new aged care system must:
 - Prioritise responsiveness and acknowledge the importance of early intervention.
 - Recognise the potential for rapidly changing support needs, particularly in the case of older people with progressive conditions and respond to these accordingly.
 - Specify timeframes for decision making around approval processes and service delivery, consistent with the aspirations of the NDIS Participant Service Guarantee.
- 9. The Department must include a list of funded aged care services within the new Aged Care Act or clarify how these will be captured underneath "subordinate legislation" and detail the time frame required for this capture.
- The list of funded aged care services to be embedded in legislation must include low and high-cost assistive technology and home modifications, as defined under AS/ISO 9999
 Assistive Products – Classification and Terminology.
- 11. The new assessment tool for aged care services must enable an individual to identify whether they have a disability and capture all relevant disability-related support needs as appropriate.
- 12. The Department must invest in strategies to build the capacity of aged care assessors to understand and respond to the unique needs of people with permanent and severe disability and improve collaborative arrangements between the aged care system and the NDIS.

Why must the Act adequately Capture the Needs of Older People with Permanent and Severe Disability?

The National Disability Insurance Scheme Act (Cth) 2013 states that an individual must be under age 65 at the time of making an access request for the scheme in order to be eligible. Those who entered the scheme prior to their 65th birthday are able to remain in the scheme as they age.

People with disability who were already 65 when the NDIS became available in their area and those who acquire a disability after their 65th birthday are excluded from the NDIS and must access their support from the aged care system.1

The Disability Support for Older Australians Program (formerly the Commonwealth Continuity of Support Programme) is often referred to in public rhetoric as a way of deflecting the need for the aged care system to respond to the needs of older people with permanent and severe disability.

However, the Disability Support for Older Australians Program (DSOA) is a closed program that is not accepting any new client entrants. It was only ever intended to support those who were in specialist disability services at the time of the NDIS rollout, but who did not meet the age eligibility requirements for the new scheme. 2 In 2020, there were only around 3,600 people accessing support through this program with no new entrants permitted. 3

This means that many older people with disability or who acquire a disability are unable to access support through the DSOA.

With no access to DSOA, the majority of older people with disability (two out of three) who are also ineligible for the NDIS are accessing their support via the aged care system.4

In 2021, The Royal Commission into Aged Care Quality and Safety released its final report, acknowledging that:

"The aged care system is not set up or funded to provide disability care, support and rehabilitation."5

The final report included several recommendations aimed at driving greater equity in the provision of support to older people with disability. Recommendation 72, for example, requires that:

"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." 6

The Special Rapporteur on the Rights of Persons with Disabilities further clarifies the need for older people with disability to be treated equitably, noting:

"States have an international obligation to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all older persons with disabilities, including by reviewing their legal and policy frameworks; prohibiting discrimination on the basis of age and/or disability; and ensuring access to rights-based community support."7

We remind the Department that Australia's Disability Strategy 2021-31 is Australia's domestic blueprint for the implementation of the Convention on the Rights of Persons with Disabilities. It requires that:

"People with disability have access to a range of supports to assist them to live independently and engage in their communities".

The outcomes referenced underneath Australia's Disability Strategy (the Strategy) apply to all people with disability. Not just those who are under the age of 65, and not just those who are eligible for an individually funded package of supports under the NDIS.

It is critical that the new Aged Care Act drives greater equity in the provision of disability-related services and supports for older people with disability, in alignment with commitments made under the Strategy.

Recommendation 1:

The new Act must give rise to:

- Obligations outlined under the Convention on the Rights of Persons with Disabilities
- Obligations outlined under Australia's Disability Strategy 2021-31, and
- Recommendation 72 from the Royal Commission into Aged Care Quality and Safety.

Objects of the New Act

The consultation paper states that subject to further consultation and consideration, the Objects proposed for inclusion are that the new Act:

"Gives effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities, the International Covenant on Economic, Social and Cultural Rights, and other relevant instruments"

AFDO asserts that the United Nations Principles for Older Persons must be referenced as one of the "other relevant instruments" referred to in the consultation paper.

We would also like to see greater alignment with the objects outlined under Section 3 of the National Disability Insurance Scheme Act (Cth) 2013, which includes the following provisions:

- Support the independence and social and economic participation of people with disability
- Promote the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community.(8)

Recommendation 2:

The objects of the new Act must reference the United Nations Principles for Older Persons and achieve greater alignment with the objectives outlined under Section 3 of the National Disability Insurance Scheme Act (Cth) 2013.

Purpose of the New Act

We would like to see greater alignment with Recommendation 3 from the Royal Commission into Aged Care Quality and Safety, which states that:

"Older people are entitled to pursue (and to be supported in pursuing) physical, social, emotional and intellectual development and to be active and engaged members of the community, regardless of their age or level of physical or cognitive capability." (9)

Recommendation 3:

The purpose of the new Act should be:

- to support older people to remain active and engaged members of their community, irrespective of their age or level of physical, sensory or cognitive capability
- To support older people to remain living in their own homes for as long as possible.

Statement of Rights

The proposed rights outlined in the consultation paper have been very poorly written and do not align with best practice standards.

AFDO recommends the Department review the statement of rights to bring it into alignment with the relevant rights outlined under the Convention on the Rights of Persons with Disabilities.

Recommendation 4:

The statement of rights must be revised to achieve greater alignment with relevant Articles of the Convention on the Rights of Persons with Disabilities, namely:

- Article 5 Equality and non-discrimination
- Article 6 Women with disabilities
- Article 9 Accessibility
- Article 10 Right to life
- Article 11 Situations of risk and humanitarian emergencies
- Article 12 Equal recognition before the law
- Article 14 Liberty and security of the person
- Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Article 16 Freedom from exploitation, violence and abuse
- Article 17 Protecting the integrity of the person
- Article 19 Living independently and being included in the community
- Article 20 Personal mobility
- Article 21 Freedom of expression and opinion, and access to information
- Article 22 Respect for privacy
- Article 25 Health
- Article 26 Habilitation and rehabilitation
- Article 28 Adequate standard of living and social protection
- Article 29 Participation in political and public life
- Article 30 Participation in cultural life, recreation, leisure and sport

Principles of the New Act

Principle four outlined in the consultation paper reads:

"Where funded aged care services are required, the aged care system should offer accessible, culturally appropriate services for all older people, regardless of their location, including people of diverse backgrounds, people with alternative service needs and vulnerable people. This could include, but is not limited to:

- First Nations people.
- people from cultural and linguistically diverse backgrounds.
- people who live in rural or remote areas.
- people who are financially or socially disadvantaged.
- veterans.
- care leavers.
- parents separated from their children by forced adoption or removal.
- people who are homeless or at risk of becoming homeless, and
- people who identify as lesbian, gay, bisexual, transgender, intersex or queer."10

We note that People with permanent and severe disability have been omitted from this list completely. This is a significant oversight when considering people with disability are most likely to require "accessible services" or have "alternate service needs".

Furthermore, we know that the provisions of the existing Aged Care Act have not adequately upheld the rights of older people with permanent and severe disability who do not meet the age eligibility requirements for the NDIS. This has resulted in many people with disability going without the support they so critically need.

This cohort must be captured as a "vulnerable population" under the new Act to prevent them from falling through the cracks and obtaining none or limited supports or services into the future.

Recommendation 5:

Older people with permanent and severe disability who do not meet the age eligibility requirements for the NDIS must be explicitly referenced underneath principle 7 of the Act.

Principle 7 outlined in the consultation paper stipulates:

"The aged care system should not be used inappropriately to address service gaps in other care sectors or systems, preventing individuals from getting the best available care to meet their individual needs, goals and preferences."

Older people with disability are fearful that this principle will be used to prevent them from accessing the support they need from the aged care system into the future. In reality, what is needed is an integrated, "no wrong door" approach to prevent people with disability from

continuing to fall through the cracks and not receive necessary supports or services. The new Act must not introduce unnecessary red tape that prevents a flexible, integrated approach to service delivery across all service systems.

Recommendation 6:

The Department of Health and Aged Care must liaise with the Disability Reform Ministerial Council and the Department of Social Services to determine a best practice approach to providing timely and equitable access to specialist disability services and supports across service systems. The new Act must not prevent older people with permanent and severe disability from accessing supports from multiple service systems depending on their individual needs and circumstances.

Principle 9 outlined in the consultation paper states that:

"The aged care system should fund aged care services, which are not unlimited, for older people most in need - taking into account the individual needs of older people, and with individuals expected to meet some of the costs of services they use where they have the financial means to do so."

This wording is far too subjective and does not adequately protect older people with higher support needs. We refer the Department to recommendation 125 from the Royal Commission into Aged Care Quality and Safety, which requires:

"Individuals who are assessed as needing social supports, assistive technologies and home modifications, or care at home should not be required to contribute to the costs of that support." (11)

This is also in keeping with recommendations put forward by the Special Rapporteur on the Rights of Persons with Disabilities in 2017, which require states parties to:

"Ensure that social protection systems include the provision of access to different forms of support for persons with disabilities, including the provision of free access to essential assistive technologies, as part of the State's health coverage and social protection schemes." (12)

While we understand there will be a limited budget for the new aged care system, it is critical that older people with higher support needs are not financially disadvantaged under these arrangements. As an example, an individual with higher support needs will be significantly disadvantaged should the new system require a co-payment for each individual service required.

Recommendation 7:

The Department must adhere to Recommendation 125 from the Royal Commission into Aged Care Quality and Safety as it works with stakeholders to develop a funding model for the new aged care Act, noting its obligation to ensure older people with disability are able to access supports on an equitable basis with participants of the NDIS.

AFDO asserts that an additional principle must be added to prioritise timely access to support, noting that the new aged care system must:

- Prioritise responsiveness and acknowledge the importance of early intervention
- Recognise the potential for rapidly changing support needs (e.g., in the case of older people with progressive conditions) and respond to these accordingly
- Specify timeframes for decision making around approval processes and service delivery, consistent with the aspirations of the NDIS Participant Service Guarantee.

Recommendation 8:

The new Act must include an additional principle relating to timely access to support, noting that the new aged care system must:

- Prioritise responsiveness and acknowledge the importance of early intervention
- Recognise the potential for rapidly changing support needs, particularly in the case of older people with progressive conditions, and respond to these accordingly
- Specify timeframes for decision making around approval processes and service delivery, consistent with the aspirations of the NDIS Participant Service Guarantee.

Funded supports

The consultation paper states that:

"A list of funded aged care services will be included in subordinate legislation.

This 'service list' will initially comprise all the types of aged services that are currently funded by the Commonwealth. It will be subsequently updated to facilitate commencement of the new Support at Home program in 2025."

The Department does not clarify what this will look like in practice. As such, AFDO questions the Department's resistance to providing a list of funded supports in the new Aged Care Act.

Additionally, we fear that the proposed timelines may cause unnecessary barriers to the effective implementation of the new Support at Home Program.

It is critical that there is a robust legislative framework in place to drive the introduction of the new Support at Home Program in 2025. Retrospectively updating legislation to make it fit the context of the new Program is likely to cause issues for consumers, who have already waited far too long for the support they need and deserve.

As an example, current aged care programs do not include any dedicated funding for high-cost assistive technology. In 2019, the Department commissioned the Australian Health Care Associates to undertake a review of Assistive Technology Programs in Australia. The review found:

"Stakeholders frequently cited inequities between the aged care, health and disability sectors as a major challenge within the AT landscape, with age seen as a major cause of inequity. For example, a consumer aged 65 years or older is ineligible for NDIS support if they were not an NDIS recipient before the age of 65. This consumer is less likely to have their AT needs met than a consumer with the same condition who is aged 64 and is eligible for NDIS funding for the rest of their lives. This was seen as creating a two-tiered system, with older people who must rely on the aged care system for AT often missing out."13,14

Evidence also exists from a more recently released research report, which found that the average spend on assistive technology and home modifications per person per year for NDIS participants was \$2,500, compared with just \$51 per person per year for aged care recipients.15

High and low cost assistive technology and home modifications must be included in the list of funded supports to be developed under the new Aged Care Act or subordinate legislation to ensure this gap is addressed once and for all.

Recommendation 9:

The Department must include a list of funded aged care services within the new Aged Care Act or clarify how these will be captured underneath "subordinate legislation" and designate an appropriate time frame.

Recommendation 10:

The list of funded aged care services to be embedded in legislation must include low and high-cost assistive technology and home modifications, as defined under AS/ISO 9999 Assistive Products – Classification and Terminology.

A single assessment process for aged care services

AFDO is very supportive of the transition to a single assessment process for aged care services.

This will reduce administrative red tape and simplify the assessment process for consumers. We note that under current assessment processes, however, there is no way for a person to disclose that they have a permanent disability.

Older people with disability frequently tell us that their needs are overlooked in the assessment process as a result.

Recommendation 11:

The new assessment tool for aged care services must enable an individual to identify whether they have a disability and capture all relevant disability-related support needs as appropriate.

Recommendation 12:

The Department must invest in strategies to build the capacity of aged care assessors to understand and respond to the unique needs of people with permanent and severe disability and improve collaborative arrangements between the aged care system and the NDIS.

Concluding comments

Thank you once again for providing AFDO with an opportunity to inform the development of a new Aged Care Act.

We hope our recommendations will be reflected in the exposure draft and look forward to providing further comment on the draft legislation once available.

Older people with disability have continued to fall through the cracks since the inception of the NDIS, despite being promised that their needs would be met under the aged care system.

It is time for this problem to be addressed once and for all.

Should you require any further information in relation to this submission, please contact AFDO's Senior Systemic Advocate, Lauren Henley on mob. 0493 623 709, or by email at lauren.henley@afdo.org.au.

http://www6.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol_act/ndisa2013341/s3.html>.

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¹¹ Royal Commission into Aged Care Quality and Safety (2021) Final report: List of recommendations, accessed 30 January 2023, retrieved from

https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf.

¹² Special Rapporteur on the Rights of Persons with Disabilities (2017) Access to rights-based support for persons with disabilities, accessed 30 January 2023, retrieved from https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/436/64/PDF/G1643664.pdf?OpenElement>.

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¹⁴ Australian Healthcare Associates, on request of the Australian Government Department of Health. (2020). Review of Assistive Technology Programs in Australia Final Report, P.33.

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