



**Australian Federation of
Disability Organisations**

New Aged Care Act
Upholding the Rights
of
Older People with Disability

Submission to the
Department of Health and Aged Care

8 March 2024

Primary author/s:

Lauren Henley

Senior Systemic Advocate

Reviewed & approved by:

Ross B. Joyce

Chief Executive Officer

Table of Contents




TABLE OF CONTENTS	2
ABOUT AFDO	3
ACKNOWLEDGEMENT	4
2. INTRODUCTORY COMMENTS	5
3. SUMMARY OF RECOMMENDATIONS	7
4. HUMAN RIGHTS CONSIDERATIONS	14
5. THE ABSENCE OF KEY ASPECTS OF THE ACT.....	17
6. THE COHORT WHO KEEP FALLING THROUGH THE CRACKS	18
7. READINESS SUPPORT FOR OLDER PEOPLE AND THE SECTOR – DSOA PARTICIPANTS	22
8. INTERFACING ARRANGEMENTS BETWEEN THE NDIS AND THE AGED CARE SYSTEM	24
9. THE ROLE OF INDEPENDENT ADVOCACY	27
10. OBJECTS OF THE ACT (SECTION 5)	28
11. DEFINITIONS AND KEY CONCEPTS (SECTION 7).....	30
12. SERVICES TO BE FUNDED UNDER THE ACT (SECTION 8).....	31
13. RESTRICTIVE PRACTICE REQUIREMENTS (SECTION 17)	33
14. STATEMENT OF RIGHTS (SECTION 20).....	35
15. STATEMENT OF PRINCIPLES (SECTION 22)	39
16. ELIGIBILITY (SECTION 49).....	40
17. FEES, PAYMENTS AND SUBSIDIES (SECTION 130)	41
18. INFORMATION MANAGEMENT (CHAPTER 7).....	42
19. CONCLUDING COMMENTS	44



AFDO Ltd. 2024

- [CC BY-NC-SA](#): AFDO provides materials it has developed under a Creative Commons Licence.
- This license allows reusers to distribute, remix, adapt, and build upon the material in any medium or format for non-commercial purposes only, and only so long as attribution is given to the creator (AFDO). If you remix, adapt, or build upon the material, you must license the modified material under identical terms.

CC BY-NC-SA includes the following elements:

- BY  – Credit must be given to the creator
- NC  – Only non-commercial uses of the work are permitted
- SA  – Adaptations must be shared under the same terms

About AFDO

The Australian Federation of Disability Organisations (AFDO), a Disabled Peoples Organisation (DPO) has been a respected & recognised national peak in the disability sector for over twenty years.

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.

AFDO's thirty-six member organisations represent disability specific & cross disability communities with a total reach of over **4 million** Australians.

Our Members:

Advocacy for Inclusion Inc. - ACT	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 - Vic	Down Syndrome Australia
Enhanced Lifestyles - SA	Physical Disability Australia
People With Disabilities WA	Polio Australia
South West Autism Network - WA	Women With Disabilities ACT
Women with Disabilities Victoria	National Mental Health Consumer & Carer Forum
Advocacy WA	All Means All
AED Legal Centre - Vic	AMAZE - Vic
Arts Access Victoria	Aspergers Victoria
Disability Advocacy & Complaints Service - SA	Explorability Inc - SA
Multiple Sclerosis Australia	Leadership Plus - Vic
National Union of Students - Disabilities Dept.	National Organisation for Fetal Alcohol Spectrum Disorder
TASC National Limited	Star Victoria Inc
Youth Disability Advocacy Service - Vic	Tourettes Syndrome of Australia

Acknowledgement

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. We pay our respects to the peoples of the lands on which these operate and to their respective Elders past and present. 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

2. Introductory comments

We thank the Department of Health and Aged Care for providing AFDO with an opportunity to inform the development of the new Commonwealth Aged Care Act.

This submission will focus on the needs of older people with disability who do not meet the age eligibility requirements for the National Disability Insurance Scheme (NDIS).

Section 22 of the National Disability Insurance Scheme Act 2013 (Cth) states that an individual must be under age 65 at the time of making an access request for the scheme to be eligible.ⁱ As such, the following cohorts are currently required to access their supports from the aged care system instead:

- People who were born with or acquired disability prior to age 65, but were over the age of 65 when the NDIS rolled out in their area, and
- People who acquire disability after they turn 65.

It is a sad fact that many of the people who are now deemed “too old” for the NDIS were instrumental in advocating for its implementation. Many of these people have now completely lost faith in governments. They have been told their needs would be met under the aged care system since the inception of the NDIS, but more than a decade later, this still fails to be the case.

In 2023, AFDO partnered with the Older Persons Advocacy Network (OPAN) to publish a joint discussion paper on access to supports for older people with disability. We have drawn on this discussion paper to inform this submission and have enclosed a copy for your reference. By 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 are happy for our submission to be published on the Department's website. As a member-based peak disability advocacy organisation, it is critical that our work is visible to our members. As such, a copy of this submission will also be made available on our website.

This submission does not reflect our full range of concerns with the exposure draft for the new Aged Care Act. Due to resourcing constraints, we have chosen to focus on ensuring the Department understands the range of needs of older people with disability and the way in which these needs differ from those of the ageing population more generally.

Our submission will also highlight a range of existing policy gaps and outline how these need to be addressed under the new Act.

There are areas of concern that we have not have sufficient time to address – such as guardianship and supported decision-making arrangements. We endorse the views put forward by our colleagues at Council on the Ageing Australia on all matters that sit outside the scope of this submission.

3. Summary of recommendations

Recommendation 1:

The exposure draft must be updated to specifically state that one of the objectives of the Act is the give rise to Australia's obligations under the Convention on the Rights of Persons with Disabilities – particularly:

- Article 19 (Right to live independently and be included in the community)
- Article 20 (Personal mobility)
- Article 26 (Habilitation and rehabilitation)

Recommendation 3:

The explanatory memorandum for the Act must clearly explain the Act's intention and purpose in relation to older people requiring disability supports. It must explicitly state that the Aged Care Act will need to facilitate the provision of disability supports to older people who would otherwise qualify for the National Disability Insurance Scheme if not for the age eligibility requirements.

Recommendation 4:

The Department of Health and Aged Care, in collaboration with the Department of Social Services, must urgently issue a public communique to outline the steps Government intends to take to ensure the timely and equitable provision of services and supports to people who would otherwise qualify for the National Disability Insurance Scheme if not for the age eligibility requirements. These people have now fallen through the cracks for over a decade, and they deserve reassurance of the fact that their needs will finally be acknowledged and addressed.

Recommendation 5:

The Department of Health and Aged Care must work collaboratively with the Department of Social Services to develop a targeted action plan underneath Australia's Disability Strategy 2021-31 for the purpose of improving access to services and supports for older people with disability. This plan must be developed in partnership with older people with disability and their representative organisations and should clarify what steps are being taken to implement:

- Recommendations 72 and 73 from the Royal Commission into Aged Care Quality and Safety, and
 - Supporting Actions 2.11 and 2.12 from the Independent Review of the NDIS.
- Recommendation 6:

Government must implement Supporting Action 2.12 from the Independent Review of the National Disability Insurance Scheme as a matter of urgency - noting that the NDIS is far better-equipped to deal with the specialist disability-related needs of DSOA participants than the aged care system.

Recommendation 7:

The new Act must facilitate the development of a shared, specialist disability assessment pathway. This assessment pathway should be co-designed by and with people with disability and their representative organisations, along with key staff from the Department of Social Services and the National Disability Insurance Agency.

Recommendation 8:

The Department of Health and Aged Care must implore the Disability Reform Ministerial Council to implement a standing agenda item that is dedicated to addressing interfacing issues affecting older people with disability who are not eligible for the NDIS. The Disability Reform Ministerial Council and/or the Department of Health and Aged Care must publish regular communiques to outline how these interfacing arrangements are being operationalised.

Recommendation 9:

The new Act must create enough flexibility for an individual to concurrently access supports from multiple service systems, such as the aged care system and the National Disability Insurance Scheme, and must not legislate arbitrary age requirements that will prevent people from accessing support from the most appropriate system to meet their individual needs and circumstances. The Australian Government must implement legislative change that will allow:

- NDIS participants to concurrently access support from the NDIS and the aged care system when necessary, irrespective of age.
- Aged care recipients with permanent disability or complex needs to concurrently access support from the aged care system and the NDIS.

Recommendation 10:

The final Act must:

- Clearly define the term “Independent advocate”, in accordance with the definition outlined under Section 9 of the NDIS Act.
- Require Government to fund an aged care advocacy program
- Establish provisions that require all individuals and entities across the aged care ecosystem to support the role of independent advocates (whether they are funded under the Aged Care Advocacy Program or the National Disability Advocacy Program).

Recommendation 11:

The provisions outlined under Section 5 (b) of the exposure draft must be updated to include the following:

- “Facilitate timely equitable access to specialist disability services and supports for older people with permanent and severe disability who do not meet the age eligibility requirements for the National Disability Insurance Scheme.” And
- “Provide early access to appropriate supports for cohorts who may require aged care services prior to age 65.”
- “Facilitate the integration of services and supports across the aged care, disability, health and mental health sectors.”

Recommendation 12:

The wording of the provision included at clause B (III) under Section 5 of the exposure draft must be amended to the following:

“ensure equitable access to, and flexible delivery of, funded aged care services that put older people first and take into account the needs of individuals, regardless of their location, background, ability, support needs and life experience”

Recommendation 13:

The term “disability” must be clearly defined under the Act. The definition that is adopted for the Act must align with the definition of disability outlined under the Convention on the Rights of Persons with Disabilities and must be framed around the social model of disability.

Recommendation 14:

The Department must adopt more inclusive language to ensure the new scheme is not solely based around frailty and ageing and is adequately equipped to respond to the needs of:

- People with age-related disability or functional decline
- People who acquire disability due to the chronic, progressive or degenerative nature of a condition or illness
- People who were born with or acquired disability prior to their 65th birthday, but who do not meet the age eligibility requirements for the NDIS.
- People over 65 who acquire disability through a non-compensable accident or injury.

Recommendation 15:

The list of supports to be specified under the Act must reflect the range of supports available under the National Disability Insurance Scheme.

Recommendation 16:

The Act must specify that an older person has the right to access funding for any allied health services they need to restore their physical and mental health to the highest level possible (and maintain it at that level for as long as possible) to maximise their independence and autonomy.

Recommendation 17:

The wording included in Section 8 must be amended to reflect the following:

“aids, assistive technology, live assistance or intermediaries that will facilitate personal mobility, communication and/or self-care, or otherwise support the participant to achieve their personal goals.”

Recommendation 18:

The new Act must facilitate the provision of funding for high and low cost assistive technology and home modifications, as well as the necessary wrap around supports that facilitate the effective implementation of these interventions. The Department must refer to the 2023 submission from the National Assistive Technology Alliance when approaching this aspect of the new aged care system.

Recommendation 19:

The Department must have regard to the following as it finalises the provisions under Section 17 of the Act:

- paragraph 30: from the concluding observations on the combined second and third reports of Australia, handed down by the CRPD Committee in 2019.
- Recommendations 6.35-6.40 from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
- The many guidance materials that have been published by the NDIS Quality and Safeguards Commission on the topic of restrictive practice.

Recommendation 20:

Section 17 of the exposure draft must be amended to mandate the use of behaviour support plans. We recommend the Department liaise with the NDIS Quality and Safeguards Commission when revising this section of the Act.

Recommendation 21:

There must be an enforcement mechanism attached to the statement of rights.

Recommendation 22:

Section 92 of the exposure draft must be amended to establish a positive duty for providers to uphold the rights of older people and deliver rights-based care. These changes should be modelled on recent amendments to the Sex Discrimination Act to require a positive duty on employers to eliminate discriminatory conduct.

Recommendation 23:

The Act must establish a requirement for providers to provide consumers with information about their rights in plain English and in other formats that are accessible to people with disability.

Recommendation 24:

The Act must:

- Establish a clear complaints mechanism for older people to raise standalone breaches of rights.
- Specify penalties associated with breaches of rights resulting from poor practice by providers, government, and regulators.

Recommendation 25:

The powers of the new Independent Statutory Complaints Commissioner must be amended to allow the Commissioner to investigate and conciliate complaints about breaches of rights under the new Act. The Commissioner should also have the power to refer matters requiring enforcement or compliance to the Aged Care Quality and Safety Commission.

Recommendation 26:

The Act must clarify that people have the right to receive inclusive and accessible services irrespective of intellectual, cognitive, neurological, sensory or physical impairment.

Recommendation 27:

The statement of rights must be updated to ensure it is applicable to services that are:

- Fully funded
- Partially funded
- Paid for out of pocket by the aged care recipient (if they wish to purchase additional services themselves)

Recommendation 28:

The statement of rights must include a provision which stipulates that older people with disability who would, if not for the age restriction, otherwise be eligible for the NDIS have the right to access services on an equitable basis with participants of the NDIS.

Recommendation 29:

The statement of rights should stipulate that an individual has the right to access services in a timely manner. The Act must clearly outline a guaranteed time frame so government can work towards funding a system where support is provided within 30 days from the date of application.

Recommendation 30:

The statement of principles must be updated to clarify that providers 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 or disability 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 31:

Section 49 of the exposure draft must be updated to clarify that an individual may be granted access to services if the funded aged care services in the service type, or the funded aged care service, will facilitate:

- Mobility
- Communication
- Self-care
- Learning, or
- Community participation.

Recommendation 32:

The Department of Health and Aged Care 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 system, noting its obligation to ensure older people with disability are able to access supports on an equitable basis with participants of the NDIS.

Recommendation 33:

The Department of Health and Aged Care must work collaboratively with the Department of Social Services to ensure the National Disability Data Asset includes systems and population measures that allow for the direct comparison of outcomes between:

- NDIS participants under the age of 65 compared with those over sixty-five who are ageing in the scheme, and
- NDIS participants (disaggregated by age) compared with people with disability who are accessing support from the aged care system.

Recommendation 34:

The Act must include a legislative requirement for the System Governor to publicly report on quarterly wait times from application through to the assessment, and from assessment to the provision of services.

4. Human rights considerations

Australia has an obligation to facilitate equitable access to services and supports for all people with disability, irrespective of age. This obligation is reinforced under a range of international human rights treaties which have been signed and ratified by the Australian Government, including:

- The International Covenant on Civil and Political Rights
- The International Covenant on Economic, Social and Cultural Rights
- The Convention on the Rights of Persons with Disabilities (CRPD).

Discrimination on the basis of age is prohibited under each of these treaties.ⁱⁱ

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.”ⁱⁱⁱ

Australia’s Disability Strategy 2021-31 is Australia’s domestic blueprint for the implementation of the CRPD. 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 policy priorities listed underneath this outcome area is as follows:

- Availability of support: Making sure people with disability have access to and receive the support services they need.
- People with complex, high needs are supported: Providing services that support those people with disability who have complex high needs.
- *Informal and carer supports: Providing enough services and alternative care arrangements to give carers of people with disability the support they need.*
- *Availability of assistive technology: Improving access to assistive technologies and aids for people with disability.^{iv}*

The outcomes referenced underneath Australia’s Disability Strategy are intended to 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.

The Special Rapporteur on the Rights of Persons with Disabilities has explicitly outlined the manner in which Governments are expected to approach the provision of services and supports to older people with disability, stating:

“States must ensure the effective access of older persons with disabilities to a wide range of community-based support services and arrangements, including personal assistance; support for decision-making; assisted living arrangements; mobility aids; assistive devices and technologies; palliative care; and community services.

These support services must be available, accessible, affordable, acceptable and adaptable to all persons with disabilities regardless of age and impairment. When designing and implementing support services, States must ensure coherence and coordination across programmes, actors and levels of government responsible for the provision of support for both persons with disabilities and older persons. States must also guarantee the continuity of benefits and services when a person moves from one system to another.”^v

In order for the rights of older people with disability to be effectively upheld into the future, the new Act must ensure equivalence of access, magnitude, and range of supports available for older people with disability who do not meet the age eligibility requirements for the NDIS.

This would best be facilitated by implementing legislative and policy change to allow people with disability over the age of 65 to concurrently access supports from both the NDIS and the aged care system.

The following recommendation from the Special Rapporteur on the Rights of Persons with Disabilities must be upheld as the Department finalises the draft bill:

“Design and implement support systems so that older persons with disabilities have access to rights- and community-based support and services that are available, accessible, adequate and affordable.”

In light of the above, the Department must ensure the new Act and the support system it seeks to administer are informed by:

- General comment No.5 on the right to live independently and be included in the community, published by the CRPD Committee in 2017.
- Recommendations from the guidelines on de-institutionalisation, published by the CRPD Committee in 2022.
- Recommendations from the report entitled, "Good practices of support systems enabling community inclusion of persons with disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2023.
- Recommendations from the report entitled, "Habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities", published by the United Nations Office for the High Commissioner for Human Rights in 2019.
- Recommendations from the report entitled, "Access to rights-based support for persons with disabilities", published by the Special Rapporteur on the Rights of Persons with Disabilities in 2017.

Recommendation 1:

The exposure draft must be updated to specifically state that one of the objectives of the Act is to give rise to Australia's obligations under the Convention on the Rights of Persons with Disabilities – particularly:

- Article 19 (Right to live independently and be included in the community)
- Article 20 (Personal mobility)
- Article 26 (Habilitation and rehabilitation)

5. The absence of key aspects of the Act

There are some significant topics that have not been adequately addressed in the exposure draft. This serves to further erode peoples' confidence in the system and also makes it difficult for stakeholders to provide considered feedback.

The exposure draft does not include any detail in relation to:

- Services and supports
- Fees and charges
- Place allocation
- Critical powers
- Review of decisions
- The use of AI programs and algorithms to make decisions.

It is our understanding that this detail is to be included in a series of new rules that will be developed to accompany the Act. It is critical that older people with disability and their representative organisations have an opportunity to provide input into these rules before they are finalised.

Recommendation 2:

Parliament must undertake an inquiry into the next version of the Bill, which must include the aspects of the exposure draft that are still missing. The Rules that are intended to accompany the Act must be available for scrutiny as part of this inquiry.

6. The cohort who keep falling through the cracks

The terms of reference for the 2011 Inquiry into Disability Support which underpinned the design and implementation of the NDIS noted that the proposed scheme was:

“Intended to cover people with disability not acquired as part of the natural process of ageing”.^{vi}

The provisions outlined under Section 22 of the National Disability Insurance Scheme Act do not, however, allow for this distinction to be clearly drawn. There is now a cohort of people who have been forced into the aged care system whose disability was “not acquired as part of the natural process of ageing”.

They were born with or had acquired their disability prior to turning 65 but were already over 65 by the time the NDIS rolled out where they lived. As such, they were unable to make an access request for the scheme prior to their 65th birthday as required under Section 22 of the Act.

The Parliamentary Joint Committee on Human Rights had expressed concern with this arrangement from as far back as 2013, noting:

“This assumes that the aged care system does or will deliver all the forms of assistance support required and is organised in accordance with the principles and operates in compliance with the obligations set out in the CRPD and the NDIS. While the incidence of disability may increase with age, the assumption that a person who has lived with disability for many years can transition without difficulty to a different system that may be organised around different principles deserves further examination.”^{vii}

A decade later, there is now an undeniable body of evidence demonstrating that older people with disability who are excluded from the NDIS are not receiving equitable access to disability services and supports.

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.”^{viii}

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.”^{ix}

Recommendation 73 states:

“By 1 July 2024, the Disability Discrimination Commissioner and the Age Discrimination Commissioner should be required, as part of the new National Disability Strategy, to report annually to the Parliament on the number of people receiving aged care with disability who are aged 65 years or older and their ability to access daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those available under the National Disability Insurance Scheme.”^x

In relation to Recommendation 72, the then Coalition Government stated that this measure would be subject to further consideration; explaining that the work to develop a new support at home program would consider the level of support available to people in aged care, including the level of support available to those individuals who would otherwise be eligible for the NDIS but for the age eligibility requirement.

This work was intended to involve collaboration between the Department of Health, the Department of Social Services and the National Disability Insurance Agency and was promised to be completed by the end of 2022.^{xi}

To-date, however, the sector has received no assurance that older people with disability accessing support from the aged care system will have their needs adequately met into the future.

In its 2023 Progress Report on the Implementation of Recommendations from the Royal Commission into Aged Care Quality and Safety, the Office of the Interim Inspector-General of Aged Care noted:

“Implementation of recommendations 72 and 73 are at a comparatively early stage. Arguably, this is reasonable — there are substantial external dependencies which are crucial to deliver both recommendations.”^{xii}

AFDO would argue that this is not reasonable when considering that a number of older people with disability have now continued to fall between the cracks of the NDIS and the aged care system for more than a decade. At minimum, Government must issue a communique outlining how it intends to work towards resolving the issues faced by older people with disability into the future.

As a recent example of how the Department continues to overlook the needs of this cohort, we have attached a document that was provided to us by Deloitte Access Economics on 16 November 2023.

The project referred to in this document is entitled, *“Research study for higher levels of in-home aged care funding: Aged care for clients with disability acquired later in life”*. This study aims to approximate the costs associated with adequately meeting the needs of people with complex support needs within the aged care system.

As the title would suggest though, the objective of this study was to, “...inform policy discussion on supporting people with acquired disability over the age of 65 years”.^{xiii} As such, the needs of those who were born with or acquired disability prior to age 65, but just happened to be too old for the NDIS when it rolled out in their area, have again been completely ignored.

We are very concerned about principle 7 included in the statement of principles referenced in the exposure draft, as this is likely to further perpetuate the issues outlined above. Principle 7 states:

“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 preventing individuals from accessing the best available services to meet the needs, goals and preferences of those individuals.”^{xiv}

The needs of this cohort have already been ignored for a decade. It is unacceptable for their needs to remain unaddressed as Government approaches the task of reforming the NDIS and the aged care system. We refer to Recommendation four from the 2019 progress report published by the Joint Standing Committee on the National disability Insurance Scheme, which has still not been implemented to-date:

“The committee recommends the Department of Health in collaboration with the Department of Social Services undertake a review of current supports and funding available for people with disability over 65 years of age, with the view to developing a strategy to address current funding and support shortfalls.”^{xv}

We are aware that the Department of Health and Aged Care did commission Australian Health Care Associates to undertake a review of assistive technology programs for older people in Australia back in 2019.^{xvi} This is still insufficient, as:

1. This study only looked at one specific aspect of the care and support ecosystem and did not explore other gaps preventing older people with disability from accessing the support they need.
2. The recommendations from this study have still not been operationalised, and
3. Government is yet to develop a strategy to address current funding and support shortfalls.

Importantly, addressing this issue may actually lead to downstream savings in other areas. This is because providing people with disability with timely access to the services and supports they need has been shown to:

- Facilitate autonomy and independence
- Increase inclusion and participation
- Improve health outcomes
- Prevent secondary health conditions
- Reduce the risk of falls
- Reduce hospital admissions.^(xvii)

While the remainder of this submission will focus on various aspects of the exposure draft for the new Aged Care Act, the Act on its own will not significantly improve the experience of older people with disability.

We would like to see the above recommendation from the Joint Standing Committee on the NDIS implemented as a matter of urgency.

The Department of Health and Aged Care must work collaboratively with the Department of Social Services to develop a targeted action plan under Australia's Disability Strategy for the purpose of improving access to services and supports for older people with disability.

Recommendation 3:

The explanatory memorandum for the Act must clearly explain the Act's intention and purpose in relation to older people requiring disability supports. It must explicitly state that the Aged Care Act will need to facilitate the provision of disability supports to older people who would otherwise qualify for the National Disability Insurance Scheme if not for the age eligibility requirements.

Recommendation 4:

The Department of Health and Aged Care, in collaboration with the Department of Social Services, must urgently issue a public communique to outline the steps Government intends to take to ensure the timely and equitable provision of services and supports to people who would otherwise qualify for the National Disability Insurance Scheme if not for the age eligibility requirements. These people have now fallen through the cracks for around a decade and they deserve reassurance of the fact that their needs will finally be acknowledged and addressed.

Recommendation 5:

The Department of Health and Aged Care must work collaboratively with the Department of Social Services to develop a targeted action plan underneath Australia's Disability Strategy 2021-31 for the purpose of improving access to services and supports for older people with disability. This plan must be developed in partnership with older people with disability and their representative organisations and should clarify what steps are being taken to implement:

- Recommendations 72 and 73 from the Royal Commission into Aged Care Quality and Safety, and
- Supporting Actions 2.11 and 2.12 from the Independent Review of the NDIS.

7. Readiness support for older people and the sector – DSOA participants

The consultation paper rightly refers to the need to keep older people updated and informed about impending changes. While this issue sits slightly outside the scope of this consultation, we are drawing it to the Department's attention for two reasons:

1. Government continues to use the Disability Support for Older Australians program (DSOA) as a way of deflecting its responsibility for making the aged care system more disability inclusive.
2. This issue relates to transitional arrangements that are taking place across the broader care and support ecosystem, with a number of DSO participants now having been informed that they will be transitioned into aged care from 1 January 2025. If this transition was to go ahead, this cohort would be directly affected by the provisions outlined in the proposed Act.

We previously referred to Recommendation four from the 2019 progress report published by the Joint Standing Committee on the National Disability Insurance Scheme. This relates to developing a strategy to address current funding and support shortfalls in relation to older people with disability who do not meet the age eligibility requirements for the NDIS.

It is worth noting that this recommendation was only partially supported by the then Coalition Government, who stated that the Commonwealth Continuity of Support Program would provide ongoing support for people aged 65 and over.

As the Department is aware, The Commonwealth Continuity of Support Program has now been replaced by the Disability Support for Older Australians Program (DSOA). It is only available to people who were receiving specialist state-funded disability services prior to the introduction of the NDIS but were already 65 when the NDIS rolled out in their area. In 2020, there were around 3,600 Australians accessing support through the DSOA.

The DSOA is a closed program which is not accepting new entrants. It is also falling short of peoples 'needs and duplicating administrative costs for Government. That's why supporting Action 2.12 from the Independent Review of the NDIS proposed DSOA clients be transitioned to the NDIS. The final report from the review stated:

"While DSOA is similar to the NDIS, having two systems operating leads to inconsistencies, inefficiency and unfairness. For example, two residents in the same home can have different funding arrangements and their care cannot be effectively coordinated." xviii

As such, Supporting Action 2.12 recommends:

“The Australian Government should implement legislative or process change to allow access to the NDIS for Disability Support for Older Australians program participants. Once all remaining Disability Support for Older Australians (DSOA) participants have moved to the NDIS or aged care system, DSOA should cease.”

The Department’s approach to this issue is in direct conflict with the recommendations and findings from the NDIS Review. We refer to the client fact sheet titled "Transition of some Disability Support for Older Australians clients into aged care", published by the Department of Health and Aged Care on 14 November 2023.

This fact sheet clearly states that from 1 January 2025, DSOA clients who live at home, access less than \$50,000 per year in funded supports, and can receive “comparable services” in the in-home aged care system will be transitioned off the DSOA and into the aged care system. It remains to be seen whether DSOA participants with more complex needs for support would receive “comparable services” in a program that just doesn’t exist at present.

Given the many failings of the Department to adequately respond to the specialist needs of people with disability to-date, this outcome is extremely doubtful. Nevertheless, the Departments fact sheet represents a significant shift in public policy that was decided upon without consultation with any DSOA participants or any disability representative organisations such as AFDO. The Departments uninformed decision will have detrimental impacts on a number of people with disability.

Recommendation 6:

Government must implement Supporting Action 2.12 from the Independent Review of the National Disability Insurance Scheme as a matter of urgency - noting that the NDIS is far better-equipped to deal with the specialist disability-related needs of DSOA participants than the aged care system.

8. Interfacing arrangements between the NDIS and the Aged Care System

People with disability who entered the NDIS prior to their 65th birthday are able to continue receiving services and supports under the scheme as they age. At present, they cannot concurrently access services from the NDIS and the aged care system. If an NDIS participant enters residential aged care or starts receiving permanent support at home through the aged care system, they cease to be a participant of the NDIS.^{xix}

This arrangement is extremely problematic and unfair for people with disability who may need to access aged care services early, but who still need access to the specialist disability services and supports that are currently only adequately funded under the NDIS.

For example, people with Down Syndrome and those with acquired brain injury, typically experience higher rates of dementia (including early onset dementia) than the general population. In fact, around 50% of people with Down Syndrome will develop dementia by age 60. People with disability may also experience ageing differently due to having a shorter life expectancy.

A study undertaken by the Australian Institute of Health and Welfare found that people who used disability services were 4.7 times more likely than the general population to die before reaching their 65th birthday.^{xx}

To give a specific example, the average life expectancy of a person with Down Syndrome in Australia is 60 years.^{xxi} This demonstrates the need for NDIS participants to be able to access aged care services prior to age 65 if their circumstances necessitate this.

We refer the Department to supporting Action 2.11 from the Independent Review of the NDIS, which recommended:

“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. The National Disability Insurance Agency and the aged care system should institute a new joint model of cooperation, including a shared assessment model. This should ensure greater choice for older participants. This will require the Australian Government to change the clause in section 29(1)(b) of the National Disability Insurance Scheme Act 2013 and allow participants over the age of 65 to have expanded access to aged care system supports, including residential aged care, while remaining eligible for complementary NDIS supports.”

AFDO agrees with this sentiment but we do not support that this measure should be restricted to NDIS participants who are ageing in the Scheme. Older people with disability who would qualify for the NDIS, if not for the age eligibility requirements, but

are now forced to access their supports from the aged care system, should also be afforded this same level of flexibility.

We also reject the arbitrary age of 65 for eligibility for the aged care system. There must be an early entry pathway for cohorts who may need to access aged care services earlier for the reasons outlined above.

Effective interfacing arrangements and case management will be critical to the success of the new aged care system, as it needs to effectively meet the needs of:

- People who experience loss of functioning as they age.
- People who acquire disability due to the chronic, progressive, or degenerative nature of a condition or illness.
- People who were born with or acquired disability prior to their 65th birthday, but who do not meet the age eligibility requirements for the NDIS.
- People over 65 who acquire disability through a non-compensable accident or injury (until such time that the National Injury Insurance Scheme ((NIIS) has been fully implemented).

We also support the proposal for a shared assessment model, and would like to see a specialist assessment pathway which triggers a specialist disability needs assessment in the following circumstances:

- An individual self-identifies that they have a permanent disability, or
- The individual satisfies the disability requirements outlined under Section 24 of the National Disability Insurance Scheme Act 2013 (Cth). These requirements are as follows:
 - (a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or the person has one or more impairments to which a psychosocial disability is attributable ; and
 - (b) the impairment or impairments are, or are likely to be, permanent; and
 - (c) the impairment or impairments result in substantially reduced functional capacity to undertake one or more of the following activities:
 - (i) communication;
 - (ii) social interaction;
 - (iii) learning;
 - (iv) mobility;
 - (v) self-care;
 - (vi) self-management; and
 - (d) the impairment or impairments affect the person's capacity for social or economic participation.^{xxii}

Recommendation 7:

The new Act must facilitate the development of a shared, specialist disability assessment pathway. This assessment pathway should be co-design by and with people with disability and their representative organisations, along with key staff from the Department of Social Services and the National Disability Insurance Agency.

Recommendation 8:

The Department of Health and Aged Care must implore the Disability Reform Ministerial Council to have a standing agenda item that is dedicated to addressing interfacing issues affecting older people with disability who are not eligible for the NDIS. The Disability Reform Ministerial Council and/or the Department of Health and Aged Care must publish regular communiques to outline how these interfacing arrangements are being operationalised. .

Recommendation 9:

The new Act must create enough flexibility for an individual to concurrently access supports from multiple service systems, such as the aged care system and the National Disability Insurance Scheme and must not legislate arbitrary age requirements that will prevent people from accessing support from the most appropriate system to meet their individual needs and circumstances. The Australian Government must implement legislative change that will allow:

- NDIS participants to concurrently access support from the NDIS and the aged care system when necessary, irrespective of age.
- Aged care recipients with permanent disability or complex needs to concurrently access support from the aged care system and the NDIS.

9. The role of independent advocacy

The exposure draft does not legislate the role of independent advocates. This is in direct conflict with the NDIS Act, which defines an independent advocate as someone who:

“(a) is independent of the Agency, the Commission and any NDIS providers providing supports or services to the person with disability; and

(b) provides independent advocacy for the person with disability, to assist the person with disability to exercise choice and control and to have their voice heard in matters that affect them; and

(c) acts at the direction of the person with disability, reflecting the person with disability's expressed wishes, will, preferences and rights; and

(d) is free of relevant conflicts of interest.”^{xxiii}

We propose that the exposure draft is updated to:

- Clearly define the term “Independent advocate”, consistent with the definition outlined under Section 9 of the NDIS Act.
- Require Government to fund an aged care advocacy program.
- Establish provisions that require all individuals and entities across the aged care ecosystem to support the role of independent advocates.

It is also critical that an older person with disability has choice and control over the type of advocacy service they wish to access. A generic aged care advocacy program may not be best placed to respond to the needs of some people with permanent, lifelong disability.

It is imperative that the Act provide flexibility for residents to access support from an independent advocate funded under the National Disability Advocacy Program where this is their preference. Advocates who are funded under the NDAP must be granted the same protections, and given the same access to aged care services and facilities, as advocates who are funded under the Aged Care Advocacy Program.

Recommendation 10:

The final Act must:

- Clearly define the term “Independent advocate”, in accordance with the definition outlined under Section 9 of the NDIS Act.
- Require Government to fund an aged care advocacy program.
- Establish provisions that require all individuals and entities across the aged care ecosystem to support the role of independent advocates (whether they are funded under the Aged Care Advocacy Program or the National Disability Advocacy Program).

10. Objects of the Act (Section 5)

The list of objectives referenced under Section 5 only refers to “older people” and “funded aged care services”. This must be rectified to ensure the rights of the cohort identified under section 6 of this submission are effectively upheld under the Act.

The Act must clarify that one of its objectives is to facilitate equitable access to disability services and supports to older people with permanent and severe disability who do not meet the age eligibility requirements for the NDIS. If this is not clearly stated, the same issues older people with disability have been battling for the past ten years are likely to be replicated under the new aged care system.

At clause B, the exposure draft states that one of the objectives of the Act is to provide a forward-looking aged care system that is designed to:

“Ensure equitable access to, and flexible delivery of, funded aged care services that put older people first and take into account the needs of individuals, regardless of their location, background and life experience.”

We would like to see the word “ability” included in this paragraph to make it more disability inclusive.

We were pleased to see that one of the objectives referenced under Section 5 relates to facilitating integrated services in other sectors where required but we do not believe this objective is explicit enough though.

We would like to see greater specificity in the final version of the Bill. The following two objectives should be included in the final Act to provide greater clarity:

1. “Provide early access to appropriate supports for cohorts who may require aged care services prior to age 65.”
2. “Facilitate the integration of services and supports across the aged care, disability, mental health and health (including acute, primary and allied health) sectors.”

Recommendation 11:

The provisions outlined under Section 5 (b) of the exposure draft must be updated to include the following:

- “Facilitate timely equitable access to specialist disability services and supports for older people with permanent and severe disability who do not meet the age eligibility requirements for the National Disability Insurance Scheme.” And
- “Provide early access to appropriate supports for cohorts who may require aged care services prior to age 65.”

- “Facilitate the integration of services and supports across the aged care, disability, health and mental health sectors.”

Recommendation 12:

The wording of the provision included at clause B (III) under Section 5 of the exposure draft be amended to the following:

“ensure equitable access to, and flexible delivery of, funded aged care services that put older people first and take into account the needs of individuals, regardless of their location, background, ability, support needs and life experience”

11. Definitions and key concepts (Section 7)

The exposure draft, as is the case with the current Aged Care Act, is based around concepts such as sickness, illness and frailty. Section 7 currently includes the following definition:

“sickness means an infirmity, illness, disease, incapacity or impairment.”

This definition is problematic, outdated and just plain offensive to people with disability. Not all people who have a disease, incapacity or impairment are “sick”. Many of our staff at AFDO, the author of this submission included, have conditions or impairments that result in disability. We are not “sick” we just have diverse needs which must be accommodated as a natural aspect of human diversity.

It is both ableist and ageist to force a person with disability to have to label themselves as “sick” or “ill” to gain access to the supports they need.

In addition the word “disability” has been omitted from the list of definitions, which is a glaring oversight. As such, we believe the new Act should include the following definition of disability:

“Disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support.”xxiv

Recommendation 13:

The term “disability” must be clearly defined under the Act. The definition that is adopted for the Act must align with the definition of disability outlined under the Convention on the Rights of Persons with Disabilities and must be framed around the social model of disability.

Recommendation 14:

The Department must adopt more inclusive language to ensure the new scheme is not solely based around frailty and ageing and is adequately equipped to respond to the needs of:

- People with age-related disability or functional decline
- People who acquire disability due to the chronic, progressive or degenerative nature of a condition or illness
- People who were born with or acquired disability prior to their 65th birthday, but who do not meet the age eligibility requirements for the NDIS.
- People over 65 who acquire disability through a non-compensable accident or injury.

12. Services to be funded under the Act (Section 8)

The fact that the list of services is yet to be determined is problematic. In order for Recommendation 72 from the Aged Care Royal Commission to be effectively upheld, however, the aged care system must offer the same range of supports that are available to NDIS participants. These include:

- Daily personal activities
- Transport to enable participation in community, social, economic and daily life activities
- Therapeutic supports, including allied health
- Assistance with household tasks to enable the individual to maintain their home environment
- Provision of aids and equipment, including setup and training
- Design and construction of home modifications, and
- Vehicle modifications.^{xxv}

It is critical that the new Act seeks to resolve some of the long-standing inequities that have prevented people with disability from accessing the support they need under the current aged care system.

As an example, the 2023 edition of the Home Care Packages Operational Manual states that funds cannot be used for allied health care if the services are not related to age related functional decline.^{xxvi}

This is in stark contrast with the range and magnitude of allied health supports that are available to younger people with disability under the NDIS.

To avoid this problem being replicated in the new aged care system, the Act must explicitly state that ***an older person has the right to access funding for any allied health services they need to restore their physical and mental health to the highest level possible (and maintain it at that level for as long as possible) to maximise their independence and autonomy.*** This wording has been directly lifted from Recommendation 36 from the Aged Care Royal Commission.

The wording included in the section in relation to assistive technology is far too restrictive and does not acknowledge the role assistive technology plays in facilitating communication and self-care in addition to mobility. We recommend the wording be adjusted to reflect the following:

“aids, assistive technology, live assistance or intermediaries that will facilitate personal mobility, communication and/or self-care, or otherwise support the participant to achieve their personal goals.”

It is critical that assistive technology is adequately funded under the new aged care system. There is no dedicated funding for high cost assistive technology or home modifications under the current system. In 2022, the Australian Assistive

Technology Equity Studies 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.^{xxvii} Older people with disability are also rarely provided with the critical wrap-around supports that are needed to facilitate the effective use of assistive technology, including:

- Individual assessment and prescription
- Timely application of modifications, informed by consumer input
- Good follow-up and evaluation, with adjustments being made where necessary
- Regular check-ins to ensure the positive impact of the modification is being maintained.

Alarming, we could not find any reference to home modifications in the exposure draft. Which is a glaring oversight when considering the critical role the home modifications industry plays in supporting ageing in place.

We note that whilst NDIS participants are able to have home modifications fully funded the exposure draft does not reference this critical support type at all.

We recommend the Department refer to the joint submission we prepared in collaboration with the National Assistive Technology Alliance (NATA) in February 2023 as it approaches the provision of assistive technology and home modifications under the new aged care system.

Recommendation 15:

The list of supports to be specified under the Act must reflect the range of supports available under the National Disability Insurance Scheme.

Recommendation 16:

The Act must specify that an older person has the right to access funding for any allied health services they need to restore their physical and mental health to the highest level possible (and maintain it at that level for as long as possible) to maximise their independence and autonomy.

Recommendation 17:

The wording included in Section 8 must be amended to reflect the following: “aids, assistive technology, live assistance or intermediaries that will facilitate personal mobility, communication and/or self-care, or otherwise support the participant to achieve their personal goals.”

Recommendation 18:

The new Act must facilitate the provision of funding for high and low cost assistive technology and home modifications, as well as the necessary wrap around supports that facilitate the effective implementation of these interventions. The Department must refer to the 2023 submission from the National Assistive Technology Alliance when approaching this aspect of the new aged care system.

13. Restrictive practice requirements (Section 17)

The Act must contribute towards a *nationally consistent legislative and administrative framework for:*

- The protection of all people with disability from the use of physical and chemical restraint and seclusion under the guise of “behaviour modification”.
- The elimination of restrictive practices in all settings.

It is critical that the Department seeks to understand the Government’s response to the following recommendations arising out of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. These recommendations will have a bearing on the provisions that must be included under Section 17:

- Recommendation 6.35 Legal frameworks for the authorisation, review and oversight of restrictive practices
- Recommendation 6.36 Immediate action to provide that certain restrictive practices must not be used
- Recommendation 6.37 Data collection and public reporting on psychotropic medication
- Recommendation 6.38 Strengthening the evidence base on reducing and eliminating restrictive practices
- Recommendation 6.39 Improving collection and reporting of restrictive practices data
- Recommendation 6.40 Targets and performance indicators to drive the reduction and elimination of restrictive practices.

We are extremely concerned about the fact that the exposure draft does not mandate the use of behaviour support plans. Instead, it requires that, “The use of restrictive practices is documented”. This does not provide adequate protection for the individual receiving aged care; nor does it provide proper accountability.

Recommendation 19:

The Department must have regard to the following as it finalizes the provisions under Section 17 of the Act:

- paragraph 30: A from the concluding observations on the combined second and third reports of Australia, handed down by the CRPD Committee in 2019.
- Recommendations 6.35-6.40 from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
- The many guidance materials that have been published by the NDIS Quality and Safeguards Commission on the topic of restrictive practice.

Recommendation 20:

Section 17 of the exposure draft must be amended to mandate the use of behavior support plans. We recommend the Department liaise with the NDIS Quality and Safeguards Commission when revising this section of the Act.

14. Statement of rights (Section 20)

The Act does not do enough to uphold, promote and protect the rights of people receiving aged care. The rights outlined under this section of the Act are not directly enforceable and under the current provisions included in the exposure draft only provide a mechanism for right to be enforced when another part of the Act is not complied with, such as the Aged Care Quality Standards or Code of Conduct.

This is particularly problematic given some rights are not explicitly stated in the Standards or the Code of Conduct. In essence, this means these rights are not enforceable. As an example, only the code of conduct is intended to apply to category 1-3 level home care services. The code of conduct does not, however, include reference to the statement of rights, nor does it include a requirement to uphold rights.

The Act also places the onus on the older person to pursue a complaint if they feel their rights have been breached. This does not provide adequate accountability. Nor will it help to imbed a human rights-based culture across the aged care sector. That is why the Act must mandate a positive duty on providers to comply with the statement of rights.

We note that one of the objectives of the Act is to give rise to Australia's obligations under the CRPD. The fact that the right to accessibility (outlined under Article 9) has been omitted from the statement of rights is just completely perplexing. While there are passing references to "accessibility" throughout the statement of rights, it is not clear what is meant by this term. It has also not been clarified in the list of definitions outlined under Section 7.

It would appear that the Department's expectations of accessible services is somewhat limited though. At Section 20 (2), the exposure draft states that an individual has the right to have their need for funded aged care services assessed, or reassessed, in a manner which is "accessible and suitable for individuals living with dementia or other cognitive impairment."

Similar wording is used elsewhere in the Act. This wording is extremely limiting and exclusionary and goes against provisions included in domestic anti-discrimination legislation.

All older people and people with disability have the right to access all aspects of the aged care system in an accessible, inclusive and equitable manner. The wording included in the statement of rights must be updated to bring it into line with terminology used in the National Disability Insurance Scheme Act 2013 (Cth). As the current statement of rights only references accessibility in relation to specific aspects of service delivery. In reality, however, all aspects of service delivery are required to be accessible under international and domestic law.

As such, we would like to see a standalone provision included in the final Act to clarify that people have the right to receive inclusive and accessible services irrespective of intellectual, cognitive, neurological, sensory, or physical impairment.

We are also concerned that the Act only appears to establish rights in relation to “funded” aged care services. This is concerning when considering that the funding of aids, equipment and assistive technology is not currently facilitated through the provisions outlined in the exposure draft. We assert that the new Act needs to establish rights in relation to aged care services that are fully or partially funded by Government, as well as any additional services that fall within the parameters of the Act that are paid for by the individual.

Frustratingly, the statement of rights does not establish any specific rights for the cohort outlined under Section 6 of this submission. As such, we would like to see an additional provision added to clarify that older people who would otherwise be eligible for the NDIS (if not for the age requirement) have the right to access services on an equitable basis with participants of the NDIS. This measure would meaningfully contribute towards the successful implementation of Recommendation 72 from the Aged Care Royal Commission.

Finally, the statement does not establish any rights in relation to the timeliness of service delivery. NDIS participants, on the other hand, have a security associated with the Participant Service Guarantee. The Guarantee establishes clear timeframes for key NDIS processes, so participants and their families understand what to expect. The Agency then reports against Participant Service Guarantee timeframes in each Quarterly Report.^{xxviii} This is also critical for the aged care system.

The statement of rights should stipulate that an individual has the right to access services in a timely manner. Equitable and timely access to aged care services must be guaranteed within 30 days of application.

Recommendation 21:

There must be an enforcement mechanism attached to the statement of rights. This could involve amending the code of conduct to include an obligation to uphold the Statement of Rights.

Recommendation 22:

Section 92 of the exposure draft must be amended to establish a positive duty for providers to uphold the rights of older people and deliver rights-based care. These changes should be modelled on recent amendments to the Sex Discrimination Act to require a positive duty on employers to eliminate discriminatory conduct.

Recommendation 23:

The Act must establish a requirement for providers to provide consumers with information about their rights in plain English and in formats that are accessible to people with disability.

Recommendation 24:

The Act must:

- Establish a clear complaints mechanism for older people to raise standalone breaches of rights.
- Specify penalties associated with breaches of rights resulting from poor practice by providers, government, and regulators.

Recommendation 25:

The powers of the new Independent Statutory Complaints Commissioner must be amended to allow the Commissioner to investigate and conciliate complaints about breaches of rights under the new Act. The Commissioner should also have the power to refer matters requiring enforcement or compliance to the Aged Care Quality and Safety Commission.

Recommendation 26:

The Act must clarify that people have the right to receive inclusive and accessible services irrespective of intellectual, cognitive, neurological, sensory or physical impairment.

Recommendation 27:

The statement of rights must be updated to ensure it is applicable to services that are:

- Fully funded.
- Partially funded.
- Paid for out of pocket by the aged care recipient (if they wish to purchase additional services themselves).

Recommendation 28:

The statement of rights must include a provision which stipulates that older people with disability who would otherwise be eligible for the NDIS (if not for the age restriction) have the right to access services on an equitable basis with participants of the NDIS.

Recommendation 29:

The statement of rights should stipulate that an individual has the right to access services in a timely manner. The Act must clearly outline a guaranteed time frame so government can work towards funding a system where support is provided within 30 days from the date of application.

15. Statement of principles (Section 22)

As with the statement of rights, the concept of timeliness appears to be completely absent from the statement of principles. We acknowledge and welcome the inclusion of the emergency provision that enables access to support without assessment in emergency situations, but would like to see a greater emphasis placed on timeliness.

Recommendation 30:

The statement of principles must be updated to clarify that providers 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.

16. Eligibility (Section 49)

Section 49 of the exposure draft stipulates that an individual may be granted access to aged care services if:

“access to the funded aged care services in the service type, or the funded aged care service, will facilitate personal mobility of the individual in the manner and at the time of the individual's choice”

It also states that an individual may be granted access to services if the service involves a:

“mobility aid or device, or assistive technology, live assistance or intermediaries that will facilitate personal mobility of the individual”

We do not understand why the exposure draft places such a strong emphasis on mobility to the exclusion of all other life domains. This wording is restrictive and quite discriminatory. It is imperative that it is updated to reflect the life domains referenced underneath the NDIS Act to achieve parity of outcomes between the two service systems.

Recommendation 31:

Section 49 of the exposure draft must be updated to clarify that an individual may be granted access to services if the funded aged care services in the service type, or the funded aged care service, will facilitate:

- Mobility
- Communication
- Self-care
- Learning, or
- Community participation.

17. Fees, payments and subsidies (Section 130)

We note that this section of the bill is yet to be drafted. We remind the Department that people with permanent and severe disability who are under the age of 65 are eligible to access fully funded services and supports under the NDIS. Failure to provide older people with disability with access to the same range of services and supports on equitable terms goes against Australia's international human rights obligations, as outlined under section 4 of this submission.

We understand that one of the rationales behind older people with disability being required to contribute to the cost of their support is the fact that someone who acquires disability after they turn 65 will have had a greater opportunity to accumulate wealth throughout the lifecycle, and will be in a better position to contribute towards the cost of their care. This logic does not hold true for those people who acquired their disability before turning 65. As noted by the Special Rapporteur on the Rights of Persons with Disabilities:

“persons with disabilities have considerably fewer opportunities to contribute to contributory schemes than persons without disabilities, owing to their higher unemployment rates, economic inactivity and informal employment.”^{xxix}

We also refer the Department to Recommendation 128 from the Royal Commission into Aged Care Quality and Safety, which states:

“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.” (xxx)

Recommendation 32:

The Department of Health and Aged Care 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 system, noting its obligation to ensure older people with disability are able to access supports on an equitable basis with participants of the NDIS.

18. Information management (Chapter 7)

The Department's consultation paper states:

“Chapter 7 also sets out the circumstances in which information obtained or generated under the new Act may be used, recorded or disclosed. These new arrangements will facilitate improved data holdings on the interaction between health and aged care data systems, consistent with Royal Commission Recommendations 67 and 108. This is expected to include data on health care services used by people accessing funded aged care services and care outcomes at a system level.”

The consultation paper does not mention how this data will intersect with relevant areas of disability policy. As previously mentioned, Australia's Disability Strategy 2021-2031 is Australia's blueprint for the domestic implementation of the CRPD. It applies to all people with disability in Australia – irrespective of age. One of the key outcome areas of the strategy focuses on personal and community support, requiring that:

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

The Disability Strategy is accompanied by an Outcomes Framework which outlines how governments will measure, track and report on outcomes for people with disability on an annual basis. To-date though, we have not seen disaggregated data which allows for the direct comparison of outcomes between:

- NDIS participants who are under 65
- NDIS participants who are over 65 and ageing in the scheme
- People with disability who are over 65 and required to access their support from the aged care system.

Commonwealth and State and territory governments are currently working together to develop the National Disability Data Asset which will make it easier to track outcomes for people with disability across different service systems.() It is critical that the Department of Health is involved in this work and is able to contribute to a nationally consistent reporting process through the use of the National Disability Data Asset.

In 2019, the Special Rapporteur on the Rights of Persons with Disabilities issued the following directive:

“States must collect comparable disability- and age-disaggregated data to identify and address the barriers faced by older persons with disabilities in exercising their rights across various spheres of life. Disaggregated data is indispensable to assessing whether older persons with disabilities are being left behind in the implementation of the 2030 Agenda.”^{xxx}

This directive also aligns with Recommendation 73 from the Royal Commission into Aged Care Quality and Safety which, as previously stated, the Australian Government has made no progress on to-date. Recommendation 73 states:

“By 1 July 2024, the Disability Discrimination Commissioner and the Age Discrimination Commissioner should be required, as part of the new National Disability Strategy, to report annually to the Parliament on the number of people receiving aged care with disability who are aged 65 years or older and their ability to access daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those available under the National Disability Insurance Scheme.”

The Act must also include a legislative requirement for the System Governor to publicly report on quarterly wait times from application through to the assessment, and from assessment to when the services start.

Recommendation 33:

The Department of Health and Aged Care must work collaboratively with the Department of Social Services to ensure the National Disability Data Asset includes systems and population measures that allow for the direct comparison of outcomes between:

- NDIS participants under the age of 65 compared with those over sixty-five who are ageing in the scheme, and
- NDIS participants (disaggregated by age) compared with people with disability who are accessing support from the aged care system.

Recommendation 34:

The Act must include a legislative requirement for the System Governor to publicly report on quarterly wait times from application through to the assessment, and from assessment to when the services start.

19. Concluding comments

Thank you once again for providing AFDO with an opportunity to inform the development of this critical new piece of legislation.

It is our hope that the aged care reforms and NDIS review will lead to real and tangible change for the many older people with disability who have been going without the support they need for far too long.

This will necessitate the Department collaborating with the Department of Social Services, the National Disability Insurance Agency, older people with disability and their representative organisations.

As such, we look forward to working collegiately with the Department to ensure the needs of older people with disability are adequately met under Australia's new aged care system.

Submission Contact:

Lauren Henley

AFDO - Senior Systemic Advocate

M: 0493 623 709

E: lauren.henley@afdo.org.au

ⁱ Commonwealth of Australia, *National Disability Insurance Scheme Act 2013 (Cth)*, Section 22: *Age requirements*, accessed 9 February 2024, retrieved from https://www5.austlii.edu.au/au/legis/cth/consol_act/ndisa2013341/s22.html.

ⁱⁱ Commonwealth of Australia, Attorney-General's Department (2024) *Rights of equality and non-discrimination*, accessed 10 February 2024, retrieved from < <https://www.ag.gov.au/rights-and-protections/human-rights-and-anti-discrimination/human-rights-scrutiny/public-sector-guidance-sheets/rights-equality-and-non-discrimination>>.

ⁱⁱⁱ Special Rapporteur on the Rights of Persons with Disabilities (2017) *Access to rights-based support for persons with disabilities*, accessed 10 January 2024, retrieved from <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/436/64/PDF/G1643664.pdf?OpenElement>.

^{iv} Australian Institute of Health and Welfare (2024) *Australia's Disability Strategy 2021–2031 Outcomes Framework: Second annual report, Personal and community support*, accessed 10 January 2024, retrieved from < <https://www.aihw.gov.au/reports/australias-disability-strategy/australias-disability-strategy-outcomes-framework/contents/personal-and-community-support>>.

^v Special Rapporteur on the Rights of Persons with Disabilities (2019) *Rights of Older Persons with Disabilities*, accessed 6 March 2024, retrieved from <<https://documents.un.org/doc/undoc/gen/n19/221/53/pdf/n1922153.pdf?token=qDTzTfNjbfvHMthcy0&fe=true>>.

^{vi} Productivity Commission (2011) *Inquiry report - Disability Care and Support, Appendix C: Disability and Aged Care Interface*, accessed 9 February 2024, retrieved from <<https://www.pc.gov.au/inquiries/completed/disability-support/report/27-disability-support-appendixc.pdf>>.

^{vii} Parliamentary Joint Committee on Human Rights. (2013). 'National Disability Insurance Scheme Bill 2012: Committee View', accessed 18 July 2023, retrieved from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/Scrutiny_reports/2013/2013/12013/c08.

^{viii} Royal Commission into Aged Care Quality and Safety (2021) Final Report: Care, Dignity and Respect. Volume 3A: The New System, accessed 17 August 2023, retrieved from <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-3a_0.pdf>.

^{ix} Royal Commission into Aged Care Quality and Safety (2021) Final report - List of recommendations, accessed 1 February 2023, retrieved from <<https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>>.

^x Royal Commission into Aged Care Quality and Safety (2021) Final report - List of recommendations, accessed 1 February 2023, retrieved from <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>.

^{xi} Commonwealth Department of Health and Aged Care (2021) Australian Government response to the final report of the Royal Commission into Aged Care Quality and Safety, accessed 9 February 2024, retrieved from <<https://www.health.gov.au/sites/default/files/documents/2021/05/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety.pdf>>.

^{xii} Commonwealth of Australia, prepared by the Interim Inspector-General of Aged Care (2023) *Progress Report: Implementation of recommendations from the Royal Commission into Aged Care Quality and Safety*, accessed 11 February 2024, retrieved from <<https://www.health.gov.au/sites/default/files/2023-10/progress-report-implementation-of-the-recommendations-of-the-royal-commission-into-aged-care-quality-and-safety.pdf>>.

^{xiii} Deloitte Access Economics (2023) *Research study for higher levels of in-home aged care funding: Aged care for clients with disability acquired later in life*, P2.

^{xiv} Commonwealth Department of Health and Aged Care (2023) *New Aged Care Act: Statement of Principles*, accessed 6 March 2024, retrieved from <https://www.health.gov.au/sites/default/files/2023-09/fact_sheet_03_-_new_aged_care_act_-_statement_of_principles_4_aug_2023.pdf>.

^{xv} Commonwealth of Australia, Joint Standing Committee on the National Disability Insurance Scheme (2019) *Progress Report: General issues around the implementation and performance of the NDIS*, accessed 10 January 2024, retrieved from <https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/Report>.

^{xvi} Australian Health Care Associates, on behalf of the Commonwealth Department of Health and Aged Care (2020) *Review of Assistive Technology Programs in Australia*, accessed 6 March 2024, retrieved from https://www.health.gov.au/sites/default/files/documents/2021/02/review-of-assistive-technology-programs-in-australia-final-report_0.pdf.

^{xvii} World Health Organization. (2020). 'Policy brief: Access to assistive technology'.

^{xviii} NDIS Independent Review Panel, on behalf of the Department of the Prime Minister and Cabinet (2023) *NDIS Review: Inclusive mainstream services coordinated with the NDIS*, accessed 9 February 2024, retrieved from <https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/part-one-unified-system-support-people-disability-1>.

^{xix} Commonwealth of Australia, *NATIONAL DISABILITY INSURANCE SCHEME ACT 2013 (Cth), Section 29: When a person ceases to be a participant*, accessed 9 February 2024, retrieved from < https://www5.austlii.edu.au/au/legis/cth/consol_act/ndisa2013341/s29.html>.

^{xx} Commonwealth of Australia, NDIS Quality and Safeguards Commission (2020) *Report: Mortality patterns among people using disability support services in Australia*, Accessed 9 February 2024, retrieved from < <https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/research-deaths-people-disability/2020-report-mortality#:~:text=Over%20the%20five%20years%20of,130%20deaths%20per%20100%2C000%20people>>.

^{xxi} Down Syndrome Australia (2022) *Life Expectancy and Ageing*, accessed 9 February 2024, retrieved from < <https://www.downsyndrome.org.au/about-down-syndrome/statistics/life-expectancy-and-ageing/>>.

^{xxii} Parliament of Australia, National Disability Insurance Scheme Act (2013) *SECT 24: Disability requirements*, accessed 12 February 2024, retrieved from <http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol_act/ndisa2013341/s24.html>.

^{xxiii} Parliament of Australia (2013) *NATIONAL DISABILITY INSURANCE SCHEME ACT 2013: SECT 9 - definitions*, accessed 7 March 2024, retrieved from https://www5.austlii.edu.au/au/legis/cth/consol_act/ndisa2013341/s9.html.

^{xxiv} World Health Organisation (2024) *Disability*, accessed 11 February 2024, retrieved from https://www.who.int/health-topics/disability#tab=tab_1.

^{xxv} Commonwealth of Australia, National Disability Insurance Agency (2024) *Supports funded by the NDIS*, accessed 12 February 2024, retrieved from <https://www.ndis.gov.au/understanding/supports-funded-ndis#:~:text=What%20types%20of%20supports%20are,economic%20and%20daily%20life%20activities>.

^{xxvi} Commonwealth of Australia, Department of Health and Aged Care (2023) *Home Care Packages Program Operational Manual: Version 1.3*, accessed 20 November 2023, retrieved from <<https://www.health.gov.au/resources/publications/home-care-packages-program-operational-manual-a-guide-for-home-care-providers?language=en>>.

^{xxvii} 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, accessed 30 January 2023, retrieved from <<https://doi.org/10.26180/21113887>>.

^{xxviii} Commonwealth of Australia, National Disability Insurance Agency (2024) *Participant Service Guarantee*, accessed 13 February 2024, retrieved from < <https://www.ndis.gov.au/about-us/policies/service-charter/participant-service-guarantee>>.

^{xxix} Special Rapporteur on the Rights of Persons with Disabilities (2017) *Access to rights-based support for persons with disabilities*, accessed 10 January 2024, retrieved from <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/436/64/PDF/G1643664.pdf?OpenElement>.

^{xxx} 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>>.

^{xxxi} United Nations (2019) *Report of the Special Rapporteur on the rights of persons with disabilities: Report on the rights of older persons with disabilities*, accessed 11 February 2024, retrieved from <https://documents.un.org/doc/undoc/gen/n19/221/53/pdf/n1922153.pdf?token=psYYd1ZA2YJSJFJ0Sy&f=e=true>.