



OPAN and AFDO Discussion Paper

Supports for older people with disability

12 September 2023

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About Older Persons Advocacy Network (OPAN)

Formed in March 2017, the Older Persons Advocacy Network (OPAN) is a national network comprised of nine state and territory organisations that have been successfully delivering advocacy, information, and education services to older people across Australia for close to 30 years.

OPAN's free services support older people and their representatives to address issues related to Commonwealth funded aged care services. OPAN is funded by the Australian Government to deliver the National Aged Care Advocacy Program (NACAP). OPAN aims to provide a national voice for aged care advocacy and promote excellence and national consistency in the delivery of advocacy services under the NACAP.

OPAN is always on the side of the older person we are supporting. It is an independent body with no membership beyond the nine SDOs. This independence is a key strength both for individual advocacy and for our systemic advocacy. In 2022 – 2023 across the OPAN network 36,904 cases of information and advocacy support were provided.

OPAN's National Older Persons Reference Group (NOPRG), ensures that OPAN hears directly from and engages with older people, carers and community members across Australia.

About the Australian Federation of Disability Organisations (AFDO)

The Australian Federation of Disability Organisations (AFDO) is a Disabled People's Organisation (DPO). We are a cross-disability representative organisation, and the national voice representing people with disability in Australia.

Our thirty-five member organisations are national and state disability advocacy organisations run by and for people with disability or their families, representing Australians with disability.

Our vision is to achieve a community where people with disability can participate in all aspects of social, economic, political and cultural life.

To achieve our mission and vision, AFDO provides policy advice and representation to government and organisations on matters that impact on the lives of people with disability. AFDO also works to inform and educate the general community about disability. This includes ensuring 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.

What are 'supports' for people with disability?

"Without adequate support, persons with disabilities are at risk of falling into neglect and institutionalization. The provision of appropriate support is necessary to the realization of the full spectrum of human rights and enables persons with disabilities to achieve their full potential, thus contributing to the overall well-being and diversity of the communities in which they live."

**UN Special Rapporteur on the rights of persons with disabilities, 2016
(paragraph 15, (1))**

"Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society. [...] Support for persons with disabilities encompasses a wide range of formal and informal interventions, including live assistance and intermediaries, mobility aids and assistive devices and technologies. It also includes personal assistance; support in decision-making; communication support, such as sign language interpreters and alternative and augmentative communication; mobility support, such as assistive technology or service animals; living arrangements services for securing housing and household help; and community services. Persons with disabilities may also need support in accessing and using general services, such as health, education and justice."

**UN Special Rapporteur on the rights of persons with disabilities, 2016
(paragraphs 13-14, (1))**

OPAN and AFDO recognise that supports for people with disability may include services provided by other professionals such as independent advocates and allied health, health and/or legal professionals.

This may include, for example, support with choosing, fitting, and learning to use assistive technologies, support in navigating systems, and support in decision-making.

Purpose of this Paper

The Older Persons Advocacy Network (OPAN) and the Australian Federation of Disability Organisations (AFDO) developed this paper to:

- A. Provide an overview of key issues relating to current services in Australia for older people with disability.
- B. Explore definitions of disability-related and ageing-related needs.
- C. Provide key statistics on unmet needs of, and reliance on informal support for, older people with disability.
- D. Describe the Australian policy ecosystem's failure to meet the needs of older people with disability.
- E. Start a solutions-focused discussion on how to meet the needs of older people with disability.

By publishing this Discussion Paper, OPAN and AFDO hope to:

- Promote the rights and needs of older people with disability.
- Educate governments, service providers and key advocacy organisations on key issues and statistics relating to older people with disability.
- Improve the quality of the discussion around meeting the needs of older people with disability through the current aged care reforms, National Disability Insurance Scheme (NDIS) Review, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Australia's Disability Strategy 2021 -2031, and other federal, state and territory reviews.
- Motivate readers to want to know more about the experiences, needs and appropriate supports for older people with disability.

Accessible Summary

Supports for older people with disability

- Adequate supports for people with disability are necessary to ensure they enjoy their human rights and to enable them to realise their full potential. This benefits individuals and society more broadly.
- Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society. Support can be provided by informal supporters such as family and friends. Support can also be provided by paid and/or professional supporters with specific qualifications and/or experience.
- Australia, on behalf of all Australians, has agreed and has an obligation to provide adequate supports for all people with disability under a range of international human rights treaties, including the:
 - International Covenant on Civil and Political Rights (ICCPR),
 - International Covenant on Economic, Social and Cultural Rights (ICESCR), and
 - Convention on the Rights of Persons with Disabilities (CRPD).
- Many reviews, inquiries and consultations since the NDIS was introduced have highlighted the significant inequalities in supports for older people with disability.
- Australian Federal, state and territory governments have not taken responsibility for addressing those inequities through coordinated and targeted strategies.

The NDIS does not meet the needs of many older people with disability

- There has been positive change to access to high quality supports for many Australians eligible for the National Disability Insurance Scheme (NDIS).
- However, many older people with disability continue to fall through the gaps and do not receive the supports they require.
- This is partly because the NDIS was never designed to provide funded services to all people with a disability, such as those with lower-level needs. It is also because of the aged-based eligibility requirement for the NDIS.

- The NDIS was supposed to support all Australians with disability across an ecosystem of supports with three tiers:
 - **Tier 1:** Promoting opportunities, increasing inclusion, and raising awareness.
 - **Tier 2:** Informing effective care and support options and making referrals to other (non-NDIS) services for lower-level or short-term functional impairments.
 - **Tier 3:** Funding individualised services for NDIS participants.
- The 2023 NDIS Review interim findings showed that this ecosystem with three tiers of supports is not functioning as intended. Almost all funding and efforts are being directed to Tier 3- the provision of supports to NDIS participants.
- The 2023 NDIS Review describes the NDIS as an 'oasis in the desert' for people with disability.
- This means that older people with lower levels of needs, or who are ineligible for the NDIS due to their age, are left to navigate a complex support system without assistance.

The age-restrictions on eligibility for the NDIS have human rights implications

- Discrimination on the basis of age is prohibited by international treaties by which Australia is bound, including:
 - Article 26 of the International Covenant on Civil and Political Rights (ICCPR),
 - Article 2(2) of the International Covenant on Economic, Social and Cultural Rights (ICESCR), and
 - Article 5(2) of the Convention on the Rights of Persons with Disabilities (CRPD).
- The NDIS Act 2013 states that only people who are under 65 years of age when they apply to access the NDIS are eligible to become participants in the Scheme.
- When the NDIS Bill was introduced, this exclusion of people aged 65 and over was justified as not being in breach of Australia's obligations under international human rights treaties because people over 65 would be able to access equivalent government-funded supports from other services.

- This paper will demonstrate that neither the aged care system nor other services are currently meeting the needs of older people with disability who are not eligible for the NDIS.

Older people with disability outside the NDIS are not having their needs met

- If older people do receive care, it is often not of the same quality or not based on the same principles as the supports provided under the NDIS.
- The 2018 Survey of Disability, Ageing and Carers (SDAC) found that 1 in 3 older people living at home with the need for assistance with everyday living assistance were having their needs only partly met or not met at all. For those receiving assistance, most supports were provided by informal (i.e., unpaid) carers.

Aged care

- The Royal Commission into Aged Care Quality and Safety concluded that “The aged care system is not set up or funded to provide disability care, support and rehabilitation”. The Commission noted inequities in supports between under the aged care system and NDIS.
- OPAN and AFDO members have many examples of these inequities and discrimination and the poorer outcomes older people with disability are facing as a result.
- The Royal Commission into Aged Care Quality and Safety recommended the inequities in supports between the NDIS and aged care systems be addressed through actions in the national disability strategy now termed, Australia’s Disability Strategy 2021–2031.
- However, Australia’s Disability Strategy 2021–2031 does not mention or reference aged care services.
- Australia’s Disability Strategy 2021–2031 also does not specifically address the inequities and discrimination leading to human rights breaches currently experienced by older people with disability.
- Aged care reforms are currently underway but there are fundamental differences and gaps between the disability and aged care sector. These differences include how human rights are upheld, the available supports, how supports are funded, and the principles the supports are based upon.

- It is unlikely that these reforms will ensure equivalence of supports for older people with disability under the NDIS and aged care systems, as required by international human rights treaties and recommended by the Royal Commission into Aged Care Quality and Safety.

Disability Support for Older Australians (DSOA) program

- The Disability Support for Older Australians (DSOA) program (formerly the Continuity of Support programme, CoS) is only available for a small number of older people with disability who were receiving state and territory disability supports prior to the NDIS rollout and who were not eligible for the NDIS on its rollout.
- The DSOA is a closed program not accepting new applications. In 2020, there were approximately 3,600 people using the CoS Programme who were expected to transition to the DSOA program.
- For those in the DSOA program, the supports provided are insufficient. The inadequacy of DSOA supports was also highlighted by the Royal Commission into Aged Care Quality and Safety.

Disability Gateway

- The Disability Gateway provides links to service providers of a range of disability services. It is developed to provide information to all people with a disability, regardless of whether they are an NDIS participant or not.
- However, the Disability Gateway does not provide guidance on which programs a person should apply for based on their needs. Instead, it is up to the individual to explore and/or to seek alternative avenues for advice (such as an allied health practitioner or independent advocacy service).

National Injury Insurance Scheme (NIIS)

- The National Injury Insurance Scheme (NIIS) was supposed to complement the NDIS and provide insurance for those whose functional impairments and related needs arose from catastrophic injuries.
- The scope and future of the NIIS is outstanding and remains to be determined.

Specialist services for older people living with psychosocial and cognitive functional impairments

- The Royal Commission into Aged Care Quality and Safety found that it is hard for older people living with psychosocial and cognitive functional impairments to access specialist services.
- The Royal Commission into Aged Care Quality and Safety also highlighted the inequities between the states and territories in these programs particularly for older people living with psychosocial and cognitive functional impairments.

Where to next? It's time to start a solutions-focussed discussion

- In the final section of this paper, OPAN and AFDO hope to promote a continued discussion on addressing the inequities and discrimination faced by older people with disability.
- We do not have the answers and are not suggesting that the answer is that all people with disability should receive funding from the same program, regardless of age. We want to see the system improved so that the inequality and discrimination cease.

OPAN and AFDO begin the discussion on how these inequities can be addressed by exploring:

- Returning to the original intention of an ecosystem of disability supports.
- Ensuring all Australians with disability receive supports that are based on the same principles and of the same quality, regardless of their age or the program where they receive funding.
- Moving away from attempting to categorise each person as having 'disability-related' or 'ageing-related' needs and then restricting them to receiving funding from only one program/system.
- Creating an integrated system of supports where people may access funding from multiple streams.
- Changing the discourse around financing disability supports for older people. This includes acknowledging the important contributions older people make to our society and the return on investment in services.
- Looking to the disability sector to lead the solution in collaboration with other sectors. This includes through allowing the experiences of the

disability sector to inform any required changes to the aged care system so that it can better support older people with disability.

- Learning from both the disability and ageing sectors to uphold the rights of older people with disability.

Part A. Overview of key issues relating to services for older people with disability

Many older people with disability are not eligible for the National Disability Insurance Scheme (NDIS)

The *National Disability Insurance Scheme Act 2013* (the NDIS Act) objects as outlined in paragraph 3 include, among others, to:

- give effect, together with other laws, to Australia's obligations under the United Nations Convention of the Rights of Persons with Disabilities, and
- facilitate the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability.

According to the NDIS Act, this is to be achieved through the provision of supports under the NDIS as well as through the provision of services by, and interactions with, other government-funded services.

While there has been positive change in nationally consistent access to high quality supports for many Australians eligible for the National Disability Insurance Scheme (NDIS) funded services, many older people with a disability continue to fall through the gaps and do not receive the supports they require.

This is partly because the NDIS was never designed to provide funded services for all people with a disability, such as those with lower-level needs, and also because of the age-based eligibility requirement for the NDIS.

People with lower-level disability support needs

Based on the initial recommendations of the 2011 Productivity Commission inquiry into disability care and support (2), the NDIS is supposed to have three tiers which:

*“**[Tier 1]** Promote opportunities for people with disability, and create awareness of the issues affecting people with disability and the advantages of inclusion.*

*“**[Tier 2]** Inform on effective care and support options, and make referrals to relevant community and mainstream services for a range of community and carer support services for people with lower level or shorter term disabilities.*

*“**[Tier 3]** Fund individualised supports.”*

NDIS Review, 2023 (p.8, (3))

However, the 2023 NDIS Review has concluded that this ecosystem with three tiers of supports for people with disability is not functioning as intended, with almost all funding and efforts being directed to Tier 3- the provision of supports to NDIS participants (3).

For example, the 2023 NDIS Review raised that the Information, Linkages and Capacity Building program is not providing the range of supports under all tiers as intended. Instead, the Information, Linkages and Capacity Building program currently focusses on providing supports only to people within the NDIS (i.e., Tier 3) instead of also doing so for people with disability not receiving NDIS funded supports (i.e., Tiers 1 and 2) as it was intended to do. Local Area Coordinators have “not been able to support people with disability outside the NDIS or deliver community capacity building and link people to services or community activities as intended.” (p.8, (3)).

“Too much time is spent navigating the ecosystem to find out where to get supports. Participants apply for and stay in the NDIS for fear of a lack of support outside of it. And people who cannot access the scheme are missing out on vital supports and services, increasing future needs. This puts great financial stress on the scheme.”

NDIS Review, 2023 (p.9, (3))

The assistive technology and home modification funding schemes are an example of the complexity of the disability system that people outside the NDIS need to navigate. The Assistive Technology for All Alliance research has found that people who are not eligible for the NDIS have to navigate a labyrinth of 108 assistive technology and home modifications funding streams administered by 87 government funders (4). Furthermore, these studies found significant inequities and inconsistencies between programs, with few providing funding support equivalent to that available under the NDIS (4).

People 65 years of age or over when they apply, are not eligible for the NDIS

The NDIS Act 2013 requires that only people who are under 65 years of age when they apply to access the NDIS are eligible to become participants in the Scheme. This arbitrary age cut-off results in the following people being excluded from NDIS supports:

- people who were born with, or acquired a disability before 65 years of age, but who did not apply to the NDIS before turning 65 years of age for any reason (including those who had already turned 65 when the NDIS was finally rolled out in their area of residence), and
- people who acquire a disability after they turn 65.

People whose functional impairments and support needs arose before the age of 65 years and were participants of the NDIS, can choose to remain with the NDIS or transfer to the aged care system after they turn 65. However, OPAN’s network has heard reports that NDIS participants with higher cost plans are being pushed by NDIS planners into moving into residential aged care during their first plan review after turning 65, despite the older person expressing a preference to remain under the NDIS.

NDIS age restriction does not allow for ageing-related disability to be distinguished from disability due to other causes

When requested to undertake an inquiry into disability care and support in 2011, the Productivity Commission's review scope was expressed as "intended to cover people with disability not acquired as part of the natural process of ageing" (p.IV, (2)).

The arbitrary age cut-off for eligibility for the NDIS does not address whether a disability has been acquired through 'the natural process of ageing'. Part C of this Discussion Paper posits that it is not possible to determine if functional impairments leading to disability are due to 'the natural process of ageing'. Furthermore, this attempt to try to exclude a group of people based on the underlying cause of a person's disability is contradictory to the NDIS Disability requirements as defined under section 24 of the NDIS Act which focuses on impairments resulting from a loss of functional capacity rather than requiring any specific diagnosis.

NDIS age restriction means older people with disability do not enjoy the same rights as younger people

The age-restrictions on eligibility for the NDIS have human rights implications where like alternative services and supports are not provided nor available. Prohibition of discrimination on the basis of age is provided for in Article 26 of the International Covenant on Civil and Political Rights (ICCPR) (5), Article 2(2) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (6), and Article 5(2) of the Convention on the Rights of Persons with Disabilities (CRPD) (7).

In 2019, the UN Committee on the Rights of Persons with Disabilities 'Concluding observations on the combined second and third periodic reports of Australia' included the recommendation that Australia:

"(e) Review disability assessment criteria for support schemes under the National Disability Insurance Scheme and align them with the human rights model of disability, ensuring adequate support for older persons with disabilities [...]" (p.2, (8)).

The potential for age-based discrimination leading to older people not enjoying the various rights promoted by the NDIS due to the requirement for applicants to be under 65 years of age on application, was raised as a concern by the

Parliamentary Joint Committee on Human Rights in its reviews of the NDIS Bill and related legislation when there were introduced in 2012–2013 (9–12). See Appendix 1 for more detail on the considerations and outcomes of these reviews which are summarised in the following paragraphs.

In summary, the conclusion from these reviews was that the only way that the age-based eligibility criteria for the NDIS will not lead to discrimination of older people and therefore breaches of rights under the ICCPR, ICESCR and CRPD would be if people ineligible for the NDIS on the basis of being over 65 years of age at the time of applying were able to access other services that will provide equivalent supports based on the same principles as the NDIS and upholding the same rights under the CRPD.

The Parliamentary Joint Committee on Human Rights was not satisfied by the information provided by the former Minister (10,13) that the aged care system would provide equivalent supports to people over 65 years of age who were ineligible for the NDIS. The Committee recommended that the NDIS age-based eligibility requirement be reviewed as part of the legislated two-year review of the NDIS Act (12).

The review of the age eligibility requirement for entry to the NDIS recommended by the Parliamentary Joint Committee on Human Rights in 2013 was never undertaken. Both the 2015 (14) and 2017 (15) reviewers concluded that considering the age-based eligibility criteria was beyond the scope of their reviews. However, both reviews noted submissions had been received on the exclusion of people over 65 and the discriminatory impact that this had on their right to access supports and equal recognition under the law.

The following sections show that neither the aged care system nor other services are currently meeting the needs of older people with disability who would otherwise be eligible for the NDIS but who were over the age of 65 years when it was rolled out in their area or when they would have applied.

Aged Care services do not meet the needs of many older people with disability

“We [the NDIS] can’t fund supports that mainstream and community services should provide, even if the other service system doesn’t actually provide it. We can’t make up for other organisations and services, where it’s their responsibility to fund or provide a service you need.”

National Disability Insurance Agency, 2021 (p.4, (16))

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

Royal Commission into Aged Care Quality and Safety, 2021 (p.346, (17))

The 2021 Final Report of the Royal Commission into Aged Care Quality and Safety also identified the inequities in philosophy and available supports for people with a disability under the aged care system when compared to the NDIS (17–19) (Appendix 2 provides more detail on key findings and the related recommendations). The Royal Commission received many submissions from disability and ageing peaks and individuals highlighting the funding inequities across all aged care services, including the Commonwealth Home Support Program, Home Care Packages and residential aged care, when compared to the supports available under the NDIS.

The cessation of many disability services, including NDIS services, for older people with a disability upon their entry into the aged care system (including community care and residential aged care) (16,20) has been raised by many members of OPAN and AFDO as an area of significant discrimination and inequality for older people with disability. As the Royal Commission into Aged Care Quality and Safety found (see Appendix 2), there are not equivalent supports available under the aged care system. The cessation of disability services, including NDIS services, upon entry into aged care results in older people with functional impairments acquired earlier in life suddenly experiencing a decrease in the amount and quality of care due to their age and eligibility for aged care services.

The Royal Commission into Aged Care Quality and Safety made two recommendations to address these inequities:

1. There will be equity of supports and outcomes for people with disability under the NDIS and aged care systems. (Recommendation 72)
2. Annual reporting on the number of people with a disability receiving aged care supports, and the equivalency of those supports to those available under the NDIS will be required under the new national disability strategy (Recommendation 73) (17,18)

The national disability strategy referred to in recommendation 73 by the Royal Commission into Aged Care Quality and Safety, named Australia's Disability Strategy 2021-2031 (21), does not mention aged care services nor does it specifically address the inequities and human rights breaches currently experienced by older people with disability in Australia.

The recommendation of the 2019 Joint Standing Committee on the National Disability Insurance Scheme that the Department of Health, in collaboration with the Department of Social Services, undertake a review and develop a strategy to address support shortfalls was only partially supported by the Department of Health (DoH). The DoH responded that "The Commonwealth CoS [Continuity of Support] program, administered by DoH, will provide ongoing support for people aged 65 and over (and Aboriginal and Torres Strait Islander people aged 50 years and over) who are currently in receipt of state-based disability services." (p.90, (22)). The DoH also noted in this response that further work was underway, including: the areas of specialist disability accommodation, aids and equipment, managing deinstitutionalisation, and support for changing circumstances (p.90, (22)).

However, recent reviews of the aged care system have not addressed these inequities. Furthermore, the following section shows that the Continuity of Support (now Disability Support for Older Australians) program is only available for a few older people with disability and is providing insufficient supports to these (see next section for more details).

The revised January 2023 version of the Home Care Packages (HCP) Operational Manual states that HCP funds cannot be used for treating a lifelong disability (except where trajectory is impacted by ageing e.g., post-polio syndrome).

Many older people with disability access aged care with disability acquired before the age of 65. This includes people who:

- were over 65 years and therefore ineligible for the NDIS upon rollout,
- had lower-level support needs earlier in life than the minimum threshold under the NDIS, and/or
- have experienced lifelong disability but whose needs have increased after the age of 65 years because of the interaction between their underlying lifelong health condition and a range of mid- and later-life health conditions.

Nevertheless, the wording included in the HCP Operational Manual raised the fear that an older person with a permanent, lifelong disability may not be considered eligible for the Home Care Packages Program if they could not demonstrate that their needs were ageing-related. This exclusion leads to unnecessary discrimination based on the age when people acquired their disability and confusion around implementation, as it is difficult to imagine any disability needs that will not change as a person ages (see Part C for a further exploration of distinguishing between disability-related and ageing-related needs).

In addition, the HCP Operational Manual states that funds cannot be used for allied health care if the services are not related to age related functional decline (23), a significant contrast to the range and magnitude of allied health supports available under the NDIS.

The Department of Health and Aged Care is undertaking a review of the in-home care system, with the intent to create a new single system to replace the current Home Care Packages and Commonwealth Home Support Program (CHSP). The Discussion Paper 'A New Program for In-Home Aged Care' released in October 2022 (24) does not mention people with disability, beyond calling for their input into the consultations. The proposed aged care reforms appear to focus on the inequities experienced by people within the aged care system due to discrepancies and barriers encountered in the current system during assessments, the determination of needs and funding levels, and service delivery.

The extent to which the quality or range of in-home aged care services will be increased remains unclear, stating 'Potentially higher levels of support at home

(pending further research)' (p.16, (24)). There is no mention in the Discussion Paper of equity of supports and outcomes for people with disability under the NDIS and aged care systems (as proposed in Recommendation 72 of the Royal Commission into Aged Care Quality and Safety, (18)). Indeed, there is no reflection on the need for a shift in the principles underpinning aged care service provision towards a social model of disability or promotion of older people's rights under the CRPD.

The Discussion Paper highlights the positive shift towards individual budgets under the new In-Home Care aged care program instead of the fixed package levels us under the current Home Care Packages program, with the maximum package capped at \$59,594 (25). It also explores how to provide recipients of in-home aged care services more choice and control over who provides services. However, there is no discussion on the caps on individual budgets, which can be assumed will be in place given that they state it remains to be determined if people will be able to receive higher levels of support at home under the new program.

In recognition of the inequities faced by older people under the NDIS versus aged care and other systems in assistive technologies and home modifications (4), the Department of Health and Aged Care released a paper in December 2022 proposing how an Assistive Technologies and Home Modifications (AT-HM) Scheme for in-home aged care could work (26).

The AT-HM scheme did not adequately address the need for wrap-around supports to ensure the effective provision of AT-HM. "Wrap around services include, but are not limited to, assessment and referral, setup and customisation, training and maintenance, and review." (p.14, (27)).

The Assistive Technology For All (ATFA) Alliance submitted a response to the AT-HM report (28) which highlighted a number of other issues on the proposed AT-HM Scheme, including:

- That any national AT-HM Scheme needs to ensure coordination with existing federal, state and territory schemes.
- The proposed principles of a future AT-HM Scheme should be revised to include greater reference to equity and diversity, older people's choices and affordability.

- That there needs to be greater consideration of how a future AT-HM scheme could ensure that clients are able to access AT-HM when they require, regardless of eligibility and financial standing.
- That there needs to be greater emphasis on independence and support programs in a future AT-HM scheme, both online and face-to-face, to improve older Australians' community access, participation in recreational facilities and social interaction.

The Department of Health and Aged Care released Consultation Paper No.1 (August 2023) on the New Aged Care Act along with fact sheets summarising key points on different topics (29–38). In line with the recommendations of the Royal Commission into Aged Care Quality and Safety, the New Act is proposed to include a Statement of Rights and a Statement of Principles.

Similar to the *National Disability Insurance Scheme Act 2013* and National Disability Standards¹, Consultation Paper No.1 on the New Aged Care Act proposes that the Objects of the new Act will include giving 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” (p.11, (29)). However, the proposed Statement of Rights under the new aged care Act do not align with the CRPD on several points and do not recognise the full breadth of rights under the CRPD (see OPAN and AFDO 2023 submissions in response to Consultation Paper No.1 on the New Aged Care Act for more details).

The April 2023 paper 'A new model for regulating Aged Care- Consultation Paper No.2 details the proposed new model and suggests that the new model could address complaints regarding breaches of the new Statement of Rights through a range of responses including requiring providers to have complaints mechanisms for 'early resolution', as well as the Aged Care Quality and Safety Commission (ACQSC)-led 'early intervention', 'restorative justice, and 'conciliation' options (39). However, it is noted that “In some, but not all

¹ The objects of the *National Disability Insurance Scheme Act 2013* are to give effect to Australia’s obligations under the CRPD and provide for the National Disability Insurance Scheme (NDIS). The NDIS Quality and Safeguards Commission’s core functions include upholding the rights of people receiving supports or services under the NDIS. In line with the NDIS, the National Standards for Disability Services for Government-funded disability employment and advocacy services are rights-based.

circumstances, identified breaches of specified rights will also involve non-compliance with provider obligations under the new framework.” (p.18, (39)).

The Statement of Principles of the new aged care system span principles related to upholding some (but not all) relevant human rights, consumer rights, and economic principles. The Statement of Principles also includes principles on which Australian systems should be responsible for providing services to older people. However, these are somewhat difficult to interpret. The wording of Principle 7 on whether there may be cases where aged care services could be ‘appropriately’ used to address service gaps in other systems. Principle 10 outlines a promising suggestion of integration with other services, including ‘strong linkages’ with the disability sector. However, whether this is referring to the ability for people to receive funding and services from multiple sectors remains unclear.

- **Principle 7.** 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.
- **Principle 10.** The aged care system should incorporate effective networks to support:
 - continuity for older people accessing funded aged care services, and
 - access to integrated services that older people may require, with strong linkages with the health, mental health, disability and community services sectors.

Department of Health and Aged Care (29,32)

Thus, there are fundamental philosophical and operational differences, as well as potential gaps for individuals to fall into between the NDIS and aged care, even in the most recent aged care reform work.

Disability Support for Older Australians (DSOA) program only accessible to a small number of older people with disability

On 1 July 2021, the Disability Support for Older Australians (DSOA) program replaced the previous Continuity of Support (CoS) programme which commenced on 1 December 2016 (40) to achieve outcomes for participants similar to those they were achieving under the state and territory disability support programs prior to the NDIS rollout (17). The NDIS Quality and Safeguards Commission regulates providers under the DSOA program, with the DSOA program administered by the Department of Health and Aged Care (41).

The DSOA is a closed program not accepting new applications. In 2020, there were approximately 3,600 people using the CoS Programme (40).

The Royal Commission into Aged Care Quality and Safety noted in its 2021 final report found that programs such as the former CoS Programme “have not consistently and comprehensively given people with disability access to the nature and extent of supports available to others under the National Disability Insurance Scheme” (p.344, (17)). The Royal Commission into Aged Care Quality and Safety noted that “It remains to be seen whether the new Disability Support for Older Australians Program will provide ‘support that is comparable’ to people on the National Disability Insurance Scheme. It is also unknown what will happen after 2027 after the Australian Government’s Budget 2023–24 announced an additional four years of funding for the DSOA program (42). Such a situation of uncertainty is not acceptable for older people with disability who are reliant on support to live with some quality of life.” (p.344, (17)).

Unfortunately, the transition from the CoS to DSOA saw no change in access to supports for older people with disability as services excluded under the CoS Programme remain excluded under the DSOA program (41). This includes community access supports not being funded under DSOA program (41) and Specialist Disability Accommodation funding (43).

OPAN members report that the state and territory programs that the CoS Programme replaced:

- required a higher level of need/supports to be eligible when compared to the NDIS needs criteria,
- had funding levels lower than the NDIS, and
- had a more limited range of supports able to be funded than the NDIS.

These discrepancies between legacy programs, the DSOA and the NDIS has resulted in DSOA clients receiving a lower level of funding and therefore support than people with comparable needs under the NDIS. Furthermore, the higher support needs eligibility criteria of the State and Territory programs the DSOA replaced when compared to the NDIS means that many people who would have been eligible for the NDIS if they were over 65 fell through the gaps between the DSOA and NDIS.

DSOA participants are able to receive funding for some 'minor additional support funding' through the Commonwealth Home Support Programme (CHSP, p.26, (44)). However, receiving CHSP funding for key supports for people with disabilities, including allied health and therapy, nursing, personal care, and respite results in the person being exited from the DSOA program (44). Older people receiving DSOA services describe being pressured to transition to the aged care system, which would make them ineligible to continue to receive DSOA funding. The DSOA Program Manual states that when a DSOA client is eligible for aged care services and the CHSP exemptions do not apply, the client must either:

1. exit the DSOA Program to access the aged care supports (the client may remain in DSOA until the aged care supports become available); or
 2. decline aged care supports and continue receiving their current level of service and funding under the DSOA Program. Their DSOA package will be capped at the level at which they are currently funded, and they will not be eligible to apply for additional DSOA funding as their needs change (excluding indexation)."
- (p.25, (44)).

This leaves DSOA participants in an unsustainable and distressing position. The highest level of Home Care Package funding (\$59,594 at the time of writing this paper (25)) would not cover the services they are receiving under the DSOA, meaning they may be unable to remain at home. People are therefore pressured to enter residential aged care, even if they would be able to remain in

their own homes with the supports available under the NDIS. This is an incredibly distressing thought for many older people who may have decades left of life left being supported by a system ill-equipped to meet their needs. It is also a potential breach of people's rights to respect for home under Article 17 of the International Covenant on Civil and Political Rights (ICCPR) (5), the right to adequate housing under Article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (6), and the right to live independently in the community under Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) (7).

"The overwhelming concern voiced by members is the at times significant disparity between the funding available under DSOA and the NDIS. In order to address this inequity and to ensure good quality of life for DSOA participants that they are supporting, many providers feel that they have little choice but to deliver the support required and cover the out of pocket cost themselves. There is also a perception that current DSOA policy assumes that the needs of people currently receiving DSOA support should and will be able to be met by the aged care system, which is not well equipped to provide the level of supports required by ageing participants with complex needs."

National Disability Services, 2023 (p.2, (43))

Disability Gateway fails to help people navigate the complex ecosystem

The Disability Gateway provides links to service providers of a range of disability services. It is developed to provide information to all people with a disability, regardless of whether they are a NDIS participant or not. However, it does not provide guidance on which programs a person should apply for based on their needs, leaving that to the individual to explore and/or to seek alternative avenues for advice (such as an allied health practitioner or advocacy service).

National Injury Insurance Scheme scope and future still to be determined

The 2011 Productivity Commission inquiry into disability care and support that recommended that the NDIS be introduced also recommended the concurrent introduction of a National Injury Insurance Scheme (NIIS) for catastrophic injuries caused by four types of accidents: motor vehicle accidents, workplace accidents, medical accidents and general accidents (occurring in the home or

community) (2). Australian governments are currently working to develop the NIS as a federated model of “state-based no-fault schemes that provide lifetime care and support for people who have sustained a catastrophic injury” (45).

Schedule A of the Bilateral Agreements between the Commonwealth and States and Territories outline the current status of the commitments by governments relating to the NIS (46–52), with the exception of Western Australia which is currently negotiating its next agreement following the expiry of its transitional agreement on 30 June 2023 (53). The Bilateral Agreements include the commitments to continue to:

- Assess the feasibility of a NIS for catastrophic general accidents in good faith, through the Standing Council on Federal Financial Relations.
- Retain the option for negotiations, through the Standing Council on Federal Financial Relations, on coverage for no fault catastrophic medical treatment accidents, following a decision by COAG in 2017 to not proceed with the medical injury stream of the NIS at this time.

Specialist services for older people living with psychosocial and cognitive functional impairments are difficult to access

The Royal Commission into Aged Care Quality and Safety noted, while all States and Territories except the Northern Territory provide older persons’ mental health services, “It is often difficult for people living in residential aged care to access specialist mental health services, such as psychologists and psychiatrists. Many staff members working in aged care are not sufficiently skilled or trained to identify and support people living with mental health conditions.” (p.69, (18)).

Furthermore, the Royal Commission into Aged Care Quality and Safety found that there are significant inequities between the States and Territories in the eligibility criteria for older persons’ mental health services, including whether or not people with changed behaviours due to dementia are eligible (18).

The Royal Commission into Aged Care Quality and Safety recommended that the Australian and State and Territory governments fund outreach mental health services for people living in residential aged care that do not exclude people living with dementia (Recommendation 59, (18)).

Part B. Exploring definitions of disability-related and ageing-related needs

There are a range of definitions of disability with the common approach being to define disability as a reduction in functional ability based on the interaction between impairments and an individual's environment. Some disability definitions also mention diagnoses and the contribution of diagnosed health/medical conditions to impairments.

Eligibility for services in Australia is most often based on a combination of how many activities of daily living are impacted, the extent of the support a person needs to undertake these activities, and sometimes also the permanency of their functional impairments.

“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.”

World Health Organization (54)

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Article 1 of the Convention on the Rights of Persons with Disabilities (CRPD) (7)

“Disability – any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months.”

Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (55)

“Functional Capacity: For the purposes of DSP [Disability Support Pension], functional capacity is what the person can, or could do, not what the person chooses to do or what others do for the person. The existence of a medical condition does not necessarily restrict functional capacity. Functional Impairment: For the purposes of DSP, a functional impairment is a loss of functional capacity affecting a person's ability to work that results from the person's medical condition”

Department of Social Services (56)

“Disability: Total or partial loss of a person's bodily or mental functions. Disability describes a person's impairment of body or function, a limitation in activities or a restriction in participation when interacting with their environment.”

National Disability Insurance Agency (57), citing the Disability Discrimination Act 1992

Some organisations and individuals attempt to group people with into ‘types of disabilities’ based on health/medical conditions and/or groupings of functional impairments (e.g., physical, psychosocial, sensory, developmental).

OPAN and AFDO do not agree with this conflation of functional impairments and/or health/medical conditions with a definition of ‘disability’ as this fails to acknowledge that disability is fundamentally a result of the interaction of any functional impairments with personal and environmental factors. This means that no two people with the same functional impairments have the same experience of disability.

The Productivity Commission's 2011 inquiry into disability supports that led to the NDIS was defined as excluding people with a disability “acquired as part of the natural process of ageing” (p.IV, (2)). However, there is no ‘natural process of ageing’ that necessarily results in consistent functional impairments contributing to disability that could be grouped together in a broad category. Furthermore, ‘old age’ is not recognised as an underlying medical condition or diagnosis under the International Classification of Diseases (ICD) (58). Although chronological age is known as a risk factor for many health conditions, the research evidence shows that every person ages differently (58). It would therefore be inappropriate to attempt to define a person's functional

impairments and/or needs as disability-related or ageing-related based on their age or the 'types' of functional impairments they have.

"Independently, chronological age is known to be of limited use for individual diagnosis, prognostication [i.e., determination of an individual's future health and/or functional impairments], and treatment guidance. Similarly, chronological age is of limited use in planning and promoting population health, healthy ageing, and social care."

Rabheru et al, 2023 (58)

The aged care Commonwealth Home Support Programme (CHSP) Program Manual recognises the variation between individuals, a lack of pre-determined trajectory for people as they age and that functional decline resulting in disabilities is therefore not an inevitable outcome of ageing. The CHSP Program Manual states that "Research suggests that the largest influencer in age-related decline is not genetics, but rather lifestyle choices. People who continue to do things for themselves tend to remain independent and live better, longer." (59).

Some people may only require maintaining a healthy and active lifestyle and to make minor adjustments to their environment (e.g., using reading glasses, using grip assist pad) to be able to live independently until their death. Others may live a healthy and active lifestyle but have physical and psychosocial functional impairments, health conditions and/or have experienced external factors (such as abuse) that lead to a more rapid functional decline with age, requiring more intensive supports to live independently.

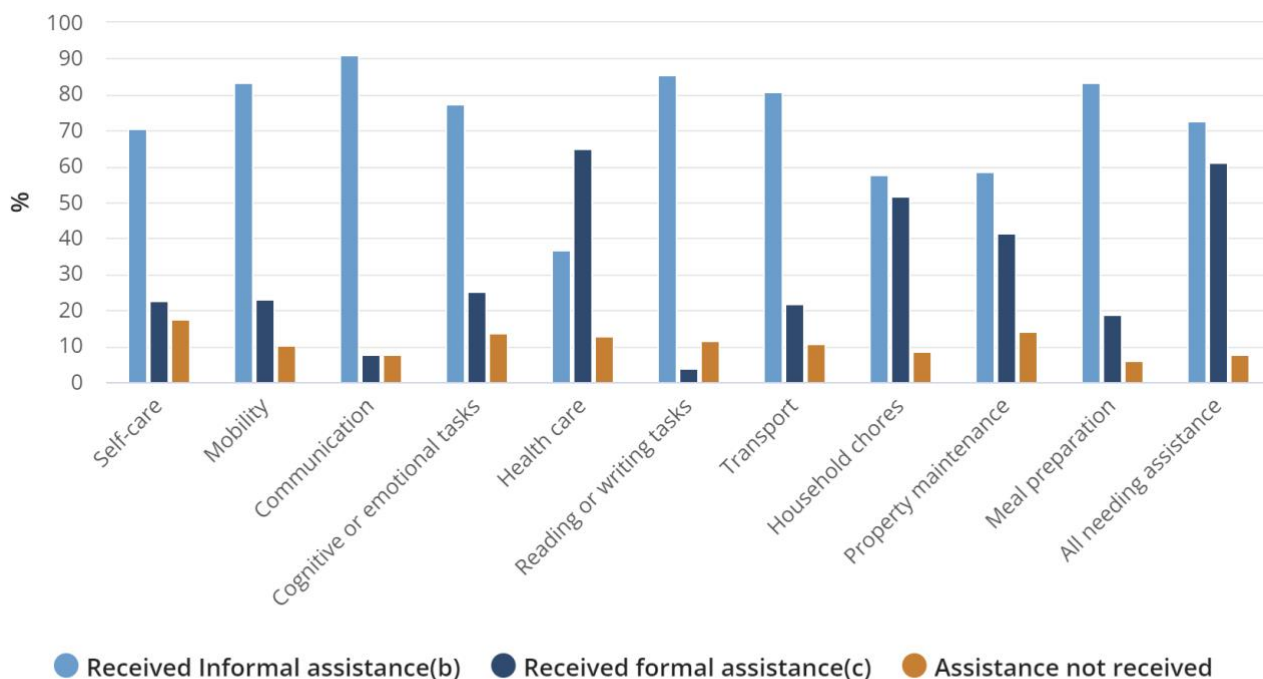
The Home Care Packages (HCP) Operational Manual states that HCP funds cannot be used for treating a lifelong disability (except where trajectory is impacted by ageing e.g., post-polio syndrome). Even if it was possible to group types of functional impairments into an 'ageing-related' group, for people diagnosed with a disability earlier in life who then experience functional decline as they age it would be impossible to classify whether the underlying cause was disability-related or ageing-related. This is because the disability would have affected so many aspects of the person's body and lifestyle and therefore their individual ageing trajectory.

Part C. Statistics on unmet needs of, and reliance on informal support for, older people with disability

The 2018 Survey of Disability, Ageing and Carers (SDAC) found that 49.3% of the 3.9 million people aged 65 years and over in Australia reported having a disability (defined as having at least one of a list of limitations, restrictions or impairments, which has lasted, or is likely to last, for at least six months) (55). Of these older people with a disability, 35.4 % were defined as having profound or severe limitation, 15 % a moderate limitation and 40.1 % a mild limitation (55).

1.3 million older people living at home needed assistance with everyday activities (i.e., 33 % of the 3.9 million people aged 65 years and over). One in three (34.1 %) older people living at home said their disability needs were only partly met or not met at all (55).

As can be seen in Figure 1, most older people needing assistance received it from informal (i.e., unpaid) providers of care, with the exception of healthcare. Spouse/partners (33.8 %), daughters (21.4 %) and sons (17.2 %) were the most common providers of informal care (55).



a. Living in households

b. Includes assistance from family, friends or neighbours

c. Includes government, private non-profit and commercial organisations

Figure 1. Persons aged 65 years and over living at home (a) who needed assistance with specific activities, by provider type. Reproduced from: 2018 Survey of Disability Ageing and Carers Summary of Findings (55).

Only 4.6 % of older people live in cared-accommodation (including hospitals, nursing homes, aged care hostels and other cared-accommodation), and most of these people are over 80 years of age (76.9 %). Almost all (97.9%) people living in cared-accommodation in 2018 had profound or severe limitations (55).

Only approximately 10% of people with a disability are eligible for the NDIS, and 49.3 % of those people with a disability who are ineligible for the NDIS are over 65 years of age (4).

Part D. Older people with disability are falling through the policy gaps

“Although ageism and ableism share common roots and consequences, inequality in older age is not the mere result of ableist biases. Ageism – the stereotyping of, and prejudice and discrimination towards, older people and older age – is a distinct form of oppression that affects older persons, including older persons with disabilities. [...]

The fragmentation of policies for older persons and for persons with disabilities results in the invisibility in law and in practice of experiences of disability in later life. Moreover, since they are perceived as a “burden” or “less deserving”, older persons with disabilities are often given lower priority in policy and therefore receive services of a lower quality, especially when there is scarcity of resources.”

**UN Special Rapporteur on the rights of persons with disabilities, 2019
(paragraph 7, (60))**

As outlined above, many reviews, inquiries and consultations since the NDIS was introduced have highlighted the significant inequalities that exist in Australia in terms of access to equivalent supports for older people with disability. However, Australian governments have not taken responsibility for addressing those inequities through coordinated and targeted strategies.

The NDIS Review 2023 observes that the NDIS has become an oasis in the desert of supports for people with a disability (3), but notes that “More time is spent arguing about who is responsible for what, and who should pay for it, than on making the ecosystem work.” (p.8, (3)).

“We have observed that support for Australians with disability is not planned, funded or governed as a whole ecosystem. There is not enough support for people with disability outside the NDIS. This is unfair and is undermining the sustainability of the NDIS. Which results in people falling through the cracks and missing out on much needed support.”

NDIS Review, 2023 (p.8, (3))

The 2019 Consultation report to inform the national disability strategy noted that people had told them about the inequities in supports and discrimination faced by older people with disability (61). However, the resulting Australia’s Disability Strategy 2021-2023 (21) does not specifically address the inequities and human rights breaches currently experienced by older people with disability in Australia.

The 2019 Joint Standing Committee on the National Disability Insurance Scheme Progress Report recommended that “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” (p.90, (22)).

However, the Department of Health only partially supported this recommendation, stating that reforms of specific funding streams currently underway and the Continuity of Support (now Disability Support for Older Australians) program will meet the needs of older people with disability (22). As noted above, this is unlikely to be the case now or into the future.

Part E. Starting a solutions-focused discussion

We need to return to the original intention of an ecosystem of disability supports

The original intention in establishing the NDIS, was that there would be a range of specialist disability support services retained and established alongside the NDIS funded supports to ensure that people of all ages enjoyed the same rights.

The 2011 Productivity Commission inquiry into disability care and support to inform the establishment of the NDIS noted that “The Australian Government has agreed to fund the disability support needs of such people under the National Health and Hospital Network Agreement with state and territory governments. It has agreed to fund specialist disability services provided under the National Disability Agreement for people aged 65 years and over (50 years and over for Indigenous Australians).” (p.16, (2)).

As shown by the many reviews and inquiries since the NDIS was established, this undertaking has not been implemented. In addition, we still lack a national strategy to ensure that older people receive the disability supports they need.

Move away from categorising people as having ‘disability-related’ or ‘ageing-related’ needs

As explored in Part C, it is difficult to think of any scenario where an older person could be defined as solely having ‘disability-related’ or ‘ageing-related’ needs.

It is therefore time to stop categorising people and instead assess each of their needs and determine which system is best able to meet that need. The aged care system may well be better equipped to provide support for some conditions as they are more common later in life, while the disability system may be better equipped to meet other needs.

Learning from disability and ageing sectors to uphold the rights of older people with disability

Previous reviews and inquiries agree that a range of inequities in support access, standard, range and underpinning principles exist between older and younger people with disability.

To ensure that older people with disability enjoy the same human rights as younger people, the solution must encompass:

- The principles underpinning the supports, including the supporting legislation and safeguards to ensure these are upheld, are the same between programs and schemes.
- There is equivalence of access, magnitude, and range of supports available to older and younger people with disability.

Given that the NDIS is acknowledged as being an overall success in promoting the rights of people with disability, this should be used as the standard all other systems must reach. However, lessons from the field of gerontology and aged care service provision must also be incorporated into these principles, such as a life-course approach to ageing.

[An integrated system of supports where people may access funding from multiple streams](#)

Older people with disability report that neither the disability system nor the aged care system are currently able to meet their needs. They describe that the NDIS, with its focus on capacity building, struggles with ageing-related functional decline and responsive reviews to meet fluctuating or sudden reductions in function.

On the other hand, people with disability receiving supports through the aged care system feel that there is too much focus on 'dying well' and not enough support to live independently in the community, as evidenced by older people with disability that results in high care needs being forced to enter residential aged care despite potentially having decades left to live.

“Supports need to recognise the importance of ageing in place for people with disabilities in residential and home settings and that support via the specialist disability service system may better meet their needs than supports available under the aged care system.”

National Disability Services, 2023 (p.4, (43))

There must be greater collaboration across government entities to identify any required legislative and policy changes to ensure older people with disability are able to receive funding for supports from the aged care and disability services sectors (including the NDIS and 'Tier 2' specialist disability support services).

The current restrictions forcing older people with disability to choose between programs and therefore which aspects of their life they are willing to compromise is discriminatory and a violation of their rights.

For example, forcing a person to choose between personal care and to be able to undertake activities of daily living if they choose to remain a DSOA client, and being able to live at home if an aged care Home Care Package recipient and receiving only a portion of funding they are receiving under the DSOA program.

Changing the discourse around financing disability supports for older people

We acknowledge the fundamental funding approach underpinning the different systems of support needs, but do not think that this precludes the exploration of solutions to ensure equivalence of supports available to people with disability.

Research for the Royal Commission into Aged Care Quality and Safety showed there is a willingness within the Australian society to pay more to ensure access to high-quality aged care (62).

Another solution originally proposed by the Productivity Commission 2011 inquiry into disability care and support was that “Regardless of which system organised the supports, after the age pension age people with a disability would be required to make a capped co-contribution to their care on the same basis as the general population, if they had the financial means.” (p.17, (2)). However, any such changes would require careful consideration of age-discrimination issues, as well as how co-contributions could be considered under an insurance scheme such as the NDIS.

Furthermore, the dialogue around older people with disability differs significantly from that of younger people with disability in that the economic and social returns of investment in supports for older people with disability is rarely considered.

The overall return on investment resulting from providing support to people with disability, including preventative and reablement approaches, allied health and assistive technology supports, has been repeatedly shown. It is acknowledged that providing supports focusing on habilitation and rehabilitation (such as those funded under the NDIS) to people with disability as early as possible can reduce the impact health conditions and injuries, reducing the need for future supports and health services (63). Indeed, Australian research has shown that

there is a two-fold return on investment for every dollar spent on assistive technology alone (4).

Based on their consideration of estimates derived from the modelling of the economic return on investment, Per Capita determined in 2021 that a conservative fiscal multiplier of 2.25 for the NDIS (i.e. for every \$1 spent on the NDIS, there is a \$2.25 return on investment) (64). Per Capita's 2021 study for National Disability Services showed that the economic impacts of the NDIS scheme were widespread and included reduced spending in other budget areas as well as positive impacts on employment and income for both NDIS participants and others, such as unpaid carers (64).

Sickness, injury or disability is the reason that 21 % of people retire in Australia (65). Adding to the economic impact of a lack of access to disability supports is the fact that 8 % of women leave the workforce to care for an ill, disabled or elderly person (compared to 2 % of men), with 36 % of retired women relying on their partner to meet their living costs of retirement (65). However, in 2018-19 approximately 143,500 people had returned to the workforce after retirement, with reasons including financial need, boredom and no longer needing to care for someone else (66).

In the 2021 census, 12% of people 65 years of age and over reported providing unpaid assistance to a person with a disability, long-term health condition or due to older age (546,539 of 4,378,088 people 65 years of age and over, (67)).

The voluntary contributions older people make to our society was highlighted by the Australian Bureau of Statistics' 2020 General Social Survey which found that people aged 55 years and over comprised:

- 36 % of all people who had undertaken unpaid voluntary work through an organisation in the last 12 months,
- 30 % of all people who had undertaken informal volunteering in the last 4 weeks, and
- 36 % of all people who had provided unpaid work/support to non-household members in the last 4 weeks (68).

Amongst people aged 70 years and over it was shown that: 28 % had undertaken unpaid voluntary work through an organisation, 26 % had undertaken informal volunteering, and 43 % had provided unpaid work/support to non-household members (68).

Time for a disability-sector led solution

The 2019 Joint Standing Committee on the National Disability Insurance Scheme Progress Report recommended that “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” (p.90, (22)).

As we have shown in this paper, the piecemeal approach to policy development in the aged care system, on a service type by service type basis, is not resulting in equivalent services for older people with disability who are not and cannot be NDIS participants compared to the services available to others with disability under the NDIS.

We do not consider that it is appropriate for the Department of Health and Aged Care to undertake a review of gaps in the support needs of older people with a disability, based on the argument that the principles and approach to policy and service delivery is fundamentally different to those applicable within the disability sector. Such a review would be unlikely to result in services becoming available to older people receiving aged care services that are equivalent to those received by older people who are NDIS participants.

The provision of equivalent services is required to ensure we are meeting our obligations under the International Covenant on Civil and Political Rights (ICCPR) (5), International Covenant on Economic, Social and Cultural Rights (ICESCR) (6), and the Convention on the Rights of Persons with Disabilities (CRPD).

We acknowledge that significant reforms of the current principles underpinning the aged care system are underway, including the inclusion of a rights-based framework in the Aged Care Act and this work should be completed so that implications of these reviews would need to be considered in any mapping of disability supports available to older people.

The design of the Support at Home program is purported to include assessment, care planning and funding and supports based on needs. If it is to meet the needs of older people with a disability, the design of this new program must be at least comparable to the quality, range and amount of supports which would be provided under the NDIS to someone under 65 years of age.

Regardless of the outcome of current reforms in aged care, we suggest that it is time for a disability-sector led solution to achieving equivalence of supports for older and younger people with disability. A first step towards this would be for the current and any future independent NDIS Reviews to:

- Cease to conclude that it is beyond the scope of their reviews and ensure that as part of their work that they consider the impacts the age-based eligibility criteria for the NDIS have on people with disability and therefore the resulting inequalities in supports received by older people and younger people with disability.
- Specifically review whether the needs of older people with disability are being met by the intended three Tiers of support specifically, Tier 1 and Tier 2 supports and Australia's Disability Strategy.

Based on the outcomes of the independent NDIS review and the earlier reviews and inquiries outlined in this paper, the NDIA and Department of Social Services could then work together with the Department of Health and Aged Care, as well as state and territory governments, to ensure equivalence of supports for all older people with disability.

Appendix 1- Overview of Parliamentary Joint Committee on Human Rights reviews of the age-based eligibility criteria for the NDIS

In its consideration of the National Disability Insurance Scheme Bill 2012 (the NDIS Bill), the Senate Standing Committee for the Scrutiny of Bills noted the potential discrimination against people over 65 years of age as a result of the NDIS eligibility requirement for people to be aged over 65 at time of application and drew the matter to the attention of the Parliamentary Joint Committee on Human Rights (PJCHR) in 2013 (69).

The Parliamentary Joint Committee on Human Rights noted that there was age-based eligibility restriction could result in discrimination against people over 65 years of age resulting in them not enjoying the various rights promoted by the NDIS. Including people's access to disability supports (9).

Further amendments to the NDIS Bill proposed amendments to the Age Discrimination Act 2004 that would mean that the actions taken under the NDIS Act 2013 would not constitute age discrimination for the purposes of the Age Discrimination Act. The Parliamentary Joint Committee on Human Rights noted this raised issues under the ICCPR, ICESCR and CPRD (11). The Committee on Human Rights reiterated its concerns regarding age-based discrimination in further reviews of the NDIS Bill and related legislation (10,12).

The Statement of Compatibility with Human Rights (the Human Rights Statement) for the NDIS Bill concluded the NDIS age-restriction "is reasonable and necessary because it supports the broader intent of an integrated system of support operating nationally and providing seamless transition through different phases of life." (p.9, Statement of Compatibility with Human Rights, (13)).

However, as noted by the Parliamentary Joint Committee on Human Rights, this justification that the age-based eligibility criteria for the NDIS would not result in discrimination due to the NDIS being part of a broader system of supports "[...] assumes that the aged care system does or will deliver all the forms of assistance and 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.” (National Disability Insurance Scheme Bill 2012, pp.4-5, paragraph 1.17, (9)).

The former Minister responded to request by the Parliamentary Joint Committee on Human Rights for confirmation that the aged care system and upcoming reforms of the aged care system would promote choice and control ((10,12), referring to former Minister’s response available in (10)).

However, after considering the information provided by the Minister in response to their concerns the Parliamentary Joint Committee on Human Rights was concerned that “there may be substantial differences between the supports provided to individuals in the aged care system compared to those on the NDIS, which could result in the inequitable treatment of people over 65 years old who acquire a disability.” (p.189, paragraph 3.27, (12)). The Committee therefore recommended that “this issue should be evaluated when the National Disability Insurance Scheme Act 2013 is reviewed after two years in accordance with section 208 of the Act.” (p.189, paragraph 3.28 (12)).

The review of the under 65 years of age requirement in the NDIS recommended by the Parliamentary Committee on Human Rights in 2013 was never undertaken.

The independent reviews of the NDIS Act by Ernst & Young in 2015 (14) and Mr David Tune AO PSM 2019 (15) both noted that submissions were made on the exclusion of people over 65 years of age and the discriminatory impact that this had on their right to access supports and equal recognition under the law.

However, these reviews made no recommendations in relation to the age requirement under the NDIS Act, stating they considered this to relate to the parameters of the scheme and therefore was beyond the scope of their reviews. Nonetheless, these reviews did address other NDIS eligibility requirements, such as disability requirements, in their reviews and make recommendations relating to these.

Appendix 2- Overview of relevant Royal Commission into Aged Care Quality and Safety findings and recommendations

The Final Report of the Royal Commission into Aged Care Quality and Safety also identified the inequities between the aged care system and NDIS concluding, “There are inconsistencies between services available under the National Disability Insurance Scheme and those available in the aged care system, especially in terms of access to supported accommodation, aids and equipment. There is much higher funding available for people in the National Disability Insurance Scheme than through aged care. [...] There are also stark differences in the level of care available under each system.” (pp.81-82, (19)). They also noted that “The disability services and aged care systems are different philosophically and operationally.” (p.345, (17)), including that “The aged care system is not set up or funded to provide disability care, support and rehabilitation.” (p.346, (17)).

“[...] older people with disability should have access to the same level of supports in aged care as would be available under the National Disability Insurance Scheme to a person under the age of 65 years, regardless of when a person acquired disability. This change is necessary to remedy a grossly unfair gap in access to supports for older people with disability.”

**Royal Commission into Aged Care Quality and Safety, 2021
(p.14, (18))**

The Royal Commission into Aged Care Quality and Safety explored the inequalities faced by older people with a disability compared to younger people in a dedicated chapter (17) and made two recommendations relating to this aim:

Recommendation 72: Equity for people with disability receiving aged care 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.

Recommendation 73: Annual reporting to Parliament by the Disability Discrimination Commissioner and the Age Discrimination Commissioner 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.

Royal Commission into Aged Care Quality and Safety, 2021 (17,18)

The Royal Commission into Aged Care Quality and Safety noted that realising recommendation 72 would require significant cooperation between the National Disability Insurance Agency and government entity responsible for management of the aged care system (17). This would include aged care increasing knowledge of disability supports available under the NDIS consistent regulatory frameworks (17).

The national disability strategy referred to in recommendation 73 by the Royal Commission into Aged Care Quality and Safety, named Australia's Disability Strategy 2021-2023 (21), does not mention aged care services nor specifically address the inequities and human rights breaches currently experienced by older people with disability in Australia.

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