Aged Care Bill 2024 [Provisions]
Submission 17



Submission to the Senate Standing Committee on Community Affairs Legislation Committee – Aged Care Bill 2024

Young People In Nursing Homes National Alliance September 2024

2

The content of this document is the intellectual property of Young People In Nursing Homes National Alliance Ltd. All rights are reserved.

When used with prior written permission, the intellectual property rights of YPINH National Alliance Ltd must always be expressly acknowledged.

### **Recommendations**

The Alliance recommends the following three actions be taken to address critical issues associated with the *Aged Care Bill 2024*<sup>1</sup>:

**1. Section 58 of the Bill should be amended** to limit access to aged care for people under 65 years to only those aged 50-64 years who are not eligible for the NDIS:

#### 58 Eligibility determination for an aged care needs assessment

The System Governor must not make an eligibility determination for an aged care needs assessment for an individual unless the System Governor considers that:

- (a) the individual:
  - (i) is aged 65 or over; or
  - (ii) is an Aboriginal or Torres Strait Islander person and is aged at least 50; or
  - (iii) is homeless, or at risk of homelessness, and is aged at least 50; and
  - (iv) if aged less than 65, is not eligible to access the National Disability Insurance Scheme:
- **2.** A new provision should be added to the Bill to recognise the status, rights and regulatory regime applying to any NDIS participant aged 50-64 years who is fully funded by the NDIS or other program and contracts with a provider to live in a residential aged care facility to receive disability supports.

That is, the Bill should recognise those who live in residential aged care facilities who are not aged care clients and do not receive aged care funding.

3. An amendment should be made to the Bill to reinstate criminal sanctions in the statutory duty of care for aged care providers as recommended by the Aged Care Royal Commission and articulated in the Exposure Draft of the Bill.

Department of Health and Aged Care (DoHAC). *Exposure draft – Aged Care Bill 2023*. Accessed on 14 February 2024 at <a href="https://www.health.gov.au/resources/publications/exposure-draft-aged-care-bill-2023?language=enf">https://www.health.gov.au/resources/publications/exposure-draft-aged-care-bill-2023?language=enf</a>

### Introduction

The Alliance welcomes the opportunity to provide this submission to the Senate Standing Committee inquiry into the *Aged Care Bill 2024*.

We broadly welcome the intention of the Commonwealth Government to introduce streamline assessments and a rights-based approach to the provision of aged care services for older Australians.

We have significant concerns, however, regarding specific issues in the Bill. Given the limited time available for response, this submission necessarily focusses on:

- the changes required to the proposed eligibility provisions for people aged under 65
  years to make them consistent with the recommendations of the Aged Care Royal
  Commission, and
- the weakening of the statutory duty of care for aged care providers.

We strongly believe that no person under 65 with a disability should be eligible for aged care services under the Aged Care Act. If people choose an aged care provider to provide their disability support, this must be funded by the NDIS or a foundation disability support program<sup>2</sup>.

# **Summary**

Over 95% of young people who are living in permanent residential aged care are NDIS participants.<sup>3</sup>

There is no reason for any NDIS participant to be forced to become an aged care client and receive standard aged care services as a substitute for required disability supports.

If an NDIS participant aged 50-64 years makes a free choice to live in a residential aged care facility, they should be entitled to live there with appropriate NDIS funding. That is, anyone eligible for the NDIS should have their supports funded by the NDIS and not the aged are system.

<sup>&</sup>lt;sup>2</sup> Bonyhady B and Paul L. *Foundational supports for all people with disability – Fact Sheet*, 2023. Accessed on 25 September 2024 at https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/preface/recommendations-and-actions

<sup>&</sup>lt;sup>3</sup> This statistic is not specifically reported by the NDIA or Aged Care but has been calculated by comparing the total YPIRAC who are NDIS participants (1595) to the total YPIRAC (1630) on 30 September 2023 (the last date before the YPIRAC reporting changed). See further at:

Australian Institute of Health and Welfare (AIHW). Young people in residential aged care – Fact Sheet
 December 2023 at <a href="https://www.gen-agedcaredata.gov.au/getmedia/d0891861-2d52-4738-b6c4-6bc7aa9eb9d1/YPIRAC-Dec-2023-Factsheet%281%29.pdf">https://www.gen-agedcaredata.gov.au/getmedia/d0891861-2d52-4738-b6c4-6bc7aa9eb9d1/YPIRAC-Dec-2023-Factsheet%281%29.pdf</a>. Total number of young people (including young First Nations people) living in permanent residential aged care on 30 September 2023 was 1630

National Disability Insurance Agency (NDIA). NDIS Quarterly report to disability ministers - 30 September 2023
 at <a href="https://www.ndis.gov.au/media/6468/download?attachment">https://www.ndis.gov.au/media/6468/download?attachment</a>. Total number of participants (including
 First Nations participants) in permanent residential aged care on 30 September 2023 was 1595.

Australian Governments should agree on who should fund the care for any young person with significant disability living in, or at risk of entering, residential aged care who is not eligible for the NDIS because they do not meet the residency or disability criteria. This group represents less than 5% of current residents. Because of their age, the Alliance supports legislative change to either allow these individuals to become NDIS participants or to fund their support at NDIS levels through the Foundation Disability Support program.

This group would include the small number of First Nations people aged 50-64 years who have been found ineligible for the NDIS but who have significant support needs. Given residential aged care has been discredited as an appropriate service for younger people (because of the inappropriate environment, the lack of choice and control, and the restricted services provided), it is inappropriate to force younger First Nations people with disability to become aged care clients and receive a lower level of supports than their peers who live in the community.

In order to protect those younger people who do move into residential aged care, the criminal penalties for serious breaches of the provider duty of care should be restored to the Bill. This will deliver on the safeguarding framework recommended by the Aged Care Royal Commission.

## Background

### How young people ended up in nursing homes

Even though the aged care system was developed to specifically support frail older Australians in the later stages of life, it has also been used as a 'safety net' for younger people with significant disability who could not access state/territory disability services. This was termed the young people in residential aged care (YPIRAC) 'problem'.

Aged care services were not designed for, or intended to support, the very different needs of young people with disability. It has been the position of Australian governments as far back as 1985, when the first attendant care program was introduced, that younger people with disability should not be living in aged care facilities. Despite this, younger people with disability have been forced to live their lives in nursing homes and die there.

The introduction of the uncapped National Disability Insurance Scheme (NDIS) in 2013 was supposed to end the need for the aged care safety net for people with disability. It should have prompted the delivery of a plan that specifically anticipated and responded the needs of young people living in residential aged care and developed safe alternatives to permit them to live in the community with dignity. Unfortunately this did not happen.

Instead, the reduction in the number of young people living in residential aged care in recent years has been mostly achieved by attrition – that is, by younger people dying in aged care or ageing out of the YPIRAC cohort and no longer being counted. While there has also been an apparent reduction in the flow of young people into residential aged care over recent years, because of exclusions to the YPIRAC data reporting, it is hard to determine whether the flow has simply been directed elsewhere (see further below).

## The fate of young people in nursing homes

While the reduction in young people living in permanent residential aged care (RAC) has been substantial in recent years, published data for the period up to 31 March 2024 reveals that:

- over 85% of young people who entered residential aged care left the YPIRAC cohort due to 'death' or 'ageing out' (that is, turning 65 years old)
- over 85% of young people who entered residential aged care died there either as a young person or after they turned 65 years
- there were:
  - o 1625 young people living in permanent residential aged care (including 244 First Nations
  - o an additional unknown number of young people were living in other aged care settings including:
    - residential aged care respite care
    - multi-purpose services (MPS) operated by state and territory governments
    - Flexible Aged Care services
    - aged care units in prisons and forensic hospitals, and
    - aged care mental health programs.

In addition, there are over 1500 people living in permanent residential aged care who entered as young people but who are now aged over 65 years.

Despite successive Commonwealth Governments endorsing a national policy of there being no person under 65 years living in permanent residential aged care by 1 January 2025, there is no longer any prospect that this target will be reached.

The stark truth is that successive government strategies to help younger people leave residential aged care and move safely to the community have been demonstrably ineffective. This failure has come at great cost to younger people with disability. As a nation, we have failed the vast majority of these younger disabled people by accepting that they will remain living in nursing homes and die there. This does not, however, mean that YPIRAC is a lost cause. It simply means we need to do better - including designing and implementing more sophisticated policy initiatives than we have had to date.

Despite most being NDIS participants before they enter, currently younger people must become aged care clients before they can enter permanent residential aged care.

As part of an agreement between the Department of Health and Aged Care (DoHAC) and the National Disability Insurance Agency (NDIA), DoHAC pays the Aged Care provider for the basic care costs (Basic Care Subsidy and Accommodation Supplement) for NDIS participants under 65

Australian Institute of Health and Welfare (AIHW). Young People in Residential Aged Care, March 2024. Accessed on 25 September 2024 at https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-agedcare

years. The NDIA annually reimburses DoHAC via a 'cross-billing' arrangement for these costs. There is, however, no specific provision in the NDIS Act that allows for this 'cross-billing' arrangement.

Other costs are charged to the participant subject to the aged care means and assets tests. The participant may get NDIS funding for in their plan for some of these costs, however there is little transparency about who gets what funding across the YPIRAC cohort.

The Alliance considers that the cross-billing arrangement for funding of aged care services for NDIS participants is antagonistic to s34 of the NDIS Act, as it substitutes aged care services for disability supports and effectively outsources the obligations of the NDIS CEO to the aged care system to determine what 'reasonable and necessary' supports the participants needs. As a result, NDIS participants who are forced to become aged care clients receive less financial support than they would if they were living in the community with only NDIS funding.

## Why is the Aged Care Bill 2024 important to people with disability?

This Bill also raises broader issues for the disability sector in light of the facts that:

• **the NDIS participant cohort is ageing** – because the introduction of the NDIS has provided people with disability with more and better supports than they were receiving in the past, their life expectancy is predicted to increase. A longer life, however, also brings with it additional complexity in relation to disability and its interaction with health. For some, it will bring the prospect of new disability that only emerges with age.<sup>5</sup>

The challenge of caring for a large cohort of people with longstanding disability as they age is something new to the Australian community

- the Australian workforce is ageing<sup>6</sup> the demographic trends of population growth in Australia indicate that the median age of Australians is increasing, and the ratio of total workforce to total population is decreasing at the same time as the number of older Australians requiring support is increasing, and
- there has been no planning for the ageing of the NDIS participant cohort there
  has been little discussion and no public consultation by the Department of Social
  Services, the Department of Health and Aged Care or the NDIA as to how people
  with disability will be supported as they age.

Without a plan for an alternative, we face the prospect of an increasing number of people 65 years+ with significant disability requiring care in residential aged care facilities that are not designed for them and by a system that is not capable of meeting their complex needs. While we have designed a system of support for younger people with significant disability

Australian Institute of Health and Welfare (AIHW). *Older Australians*, 2 July 2024. Accessed on 25 September 2024 at <a href="https://www.aihw.gov.au/reports/older-people/older-australians/contents/demographic-profile">https://www.aihw.gov.au/reports/older-people/older-australians/contents/demographic-profile</a>

\_

<sup>&</sup>lt;sup>5</sup> Alzheimer's Association UK. *Down Syndrome and Alzheimer's Disease*. Access on 25 September 2024 at <a href="https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome">https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome</a>

(NDIS) we have not properly contemplated how that system will support those individuals into their old age.

The principles that are applied to younger people with disability, and whether aged care should substitute for disability support, have resonance for all NDIS participants as they age.

## What's the connection with the YPIRAC Strategy 2020-25?

The Young People in Residential Aged Care (YPIRAC) Strategy 2020-25<sup>7</sup> is a statement of Australian Government policy on young people living in residential aged care. It set three targets for YPIRAC:

Target 1: No people under the age of 65 entering residential aged care by 2022

Target 2: No people under the age of 45 living in residential aged care by 2022

Target 3: No people under the age of 65 living in residential aged care by 2025

The first two targets have not been met. As of 31 March 2024, there were 1625 young people living in residential aged care. There is no current strategy that has any prospect of meeting Target 3 by the deadline of January 2025.

The monitoring of the numbers of YPIRAC is done via the *Young people in residential aged care report*<sup>8</sup> (also referred to as the YPIRAC Data Dashboard) published by the Australian Institute of Health and Welfare (AIHW).

The Alliance has recently become aware that **First Nations people aged 50-64 years have been removed from the count for the purposes of the YPIRAC Target 3**. This is ostensibly because First Nations people are eligible for aged care from 50 years of age.

The Alliance understands that the Department of Social Services has advanced plans to also remove people aged 50-64 years who are homeless or at risk of homelessness from the count for the purposes of Target 3, also on the basis that these young people are eligible for aged care.

#### It should be noted that:

 there has been no public announcement of these decisions – the information is included in a footnote to the tables published in the YPIRAC Dashboard

Commonwealth Department of Social Services. (2020). Young People in Residential Aged Care Strategy 2020-25. Accessed on 25 September 2024 at <a href="https://www.dss.gov.au/sites/default/files/documents/09">https://www.dss.gov.au/sites/default/files/documents/09</a> 2020/dss younger people in residential aged care v5-1.pdf

<sup>&</sup>lt;sup>8</sup> Australian Institute of Health and Welfare (AIHW). *Young People in Residential Aged Care Report*. Accessed on 25 September 2024 at <a href="https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care">https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care</a>

- when published in 2020, the YPIRAC Strategy specifically noted that people who were First Nations, homeless or at risk of homelessness aged 50-64 years who were eligible for aged care services were to be counted towards the YPIRAC Targets
- every young person aged 50-64 years entering aged care must already fulfill one of the criteria slated for exclusion from the YPIRAC count (that is, they are First Nations, homeless or at risk of homelessness)
- no young person will leave aged care as a result of being removed from the Target 3 count, and
- once these administrative exclusions are implemented, the official number of young people living in aged care is expected to artificially reduce to just those who are aged under 50 years around 32 people as at 31 March 2024.

The Committee should note carefully that, in making young people eligible for aged care, the Bill will effectively remove them from being counted as young people living in residential aged care (YPIRAC).

While this may assist the Government in technically achieving the remaining YPIRAC Target, it does nothing to reduce the actual number of young people living in aged care.

## What's the connection with the NDIS Act?

The National Disability Insurance Act (NDIS Act) has recently been amended, including the addition of s10. This amendment, among other things, empowers the Minister to – for the first time - make lists of what supports are to be considered 'NDIS Supports' and what supports are to be considered 'Not NDIS Supports'. The NDIA has recently sought consultation with the disability sector regarding draft s10 lists.<sup>9</sup>

The Act now states that NDIS participants may only expend their participant plan funds on things and services that are 'NDIS Supports' and not on things and services that are 'Not NDIS Supports'.

The draft s10 lists recently circulated by the NDIA listed aged care on the 'Not NDIS Supports' list, with a 'carve out' (exception) for people aged 50-64 years who 'choose' to live in residential aged care and purchase their supports from an aged care provider. It should be noted that because of the 'cross-billing' arrangement in place, participants in aged care do not purchase their supports directly from an aged care provider and have no ability to negotiate a service agreement with their provider with funding from their NDIS plan (as **every other** NDIS participant does).

Section 29(1)(b) of the NDIS Act states that participants who enter permanent residential aged care before the age of 65 years can preserve their access to NDIS funding beyond the age of 65. If, however, they enter permanent residential aged care for the first time after the

\_

Commonwealth Department of Social Services. Consultation on draft lists of NDIS Supports. Accessed on 25 September 2024 at <a href="https://engage.dss.gov.au/consultation-on-draft-lists-of-ndis-supports/">https://engage.dss.gov.au/consultation-on-draft-lists-of-ndis-supports/</a>

age of 65 they automatically lose this access. Since the addition of s10, however, this preservation provision may be meaningless as anyone over the age of 65 would not be able to buy aged care services with their NDIS funding as aged care services are on the 'Not NDIS Supports' list.

In summary, the changes to the NDIS Act are expected to result in more participants losing their entitlement to NDIS funding as they (a) move into residential aged care and then turn 65 or (b) move into residential aged care after they turn 65. Either way, the apparent intention of the Commonwealth Government is for the Aged Care system - rather than the NDIA - to become the primary provider of funded care to people with disability over the age of 65.

It is not clear whether the Commonwealth has coordinated its policy position in regard to the issue of people with disability in aged care across its various agencies. There is, however, an obvious opportunity for the NDIA, DoHAC and DSS to collaborate to resolve these anomalies before the *Aged Care Bill* is passed.

The Alliance has previously called for the repeal of s29(1)(b) of the NDIS Act (which stipulates that NDIS access is lost after moving into permanent residential aged care) because it is discriminatory and is unnecessary now that the NDIS is no longer in its trial phase. This call was endorsed by the NDIS Review<sup>10</sup> in its recommendations however, the repeal was not part of the recent NDIS Act amendments. This needs to be prioritised for the next set of amendments to the NDIS legislation.

# **Impacts of the Aged Care Bill 2024**

The Aged Care Bill 2024 creates - for the first time in Australian history - a legislated age criteria. It also creates, for the first time, a specific legislated provision to allow access to aged care services for young people with disability aged 50-64 years who are First Nations, homeless or at risk of homelessness, assuming they also meet the disability requirements for access (that is, assessed as having high support needs).

If passed in its current form the Bill:

# 1. Legislates - for the first time - young people living permanently in residential aged care

This is a stunning reversal of the longstanding bipartisan Australian Government policy of no young people living in residential aged care. It formally acknowledges that the targets set out in the *YPIRAC Strategy 2020-2025*<sup>11</sup> - targets which remain Australian Government policy<sup>12</sup> - have not<sup>13</sup> and will not be met.

Bonyhady B and Paul L. Working together to deliver the NDIS – Recommendations and actions, 7 December 2023. Accessed on 25 September 2024 at https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/preface/recommendations-and-actions

<sup>&</sup>lt;sup>11</sup> Australian Department of Social Services. (2020). *Young People in Residential Aged Care – Strategy 2020-25*. Accessed on 25 September 2025 at

By making some people under 65 eligible for aged care services, the Bill codifies placement of younger people in residential aged care in direct contradiction of the Commonwealth Government's acceptance of Recommendation 74 of the Aged Care Royal Commission on this issue.<sup>14</sup>

There is no commensurate requirement on the NDIA (or Commonwealth, state and territory governments in the case of those not eligible for the NDIS) to guarantee funding or provision of suitable accommodation and services to support younger people with disability to live safely and with dignity in the community.

This allows these entities to continue using aged care as a low-cost or no-cost substitute for the supports they should be providing.

The prospect of cranking up the flow of young people into residential aged care - after decades of attempting to turn off the flow and help those in residential aged care to leave - is deeply disappointing. It suggests that either there has been no consultation between the various Commonwealth Government departments or there is a broader agenda in play which is not yet public.

# 2. Creates a power for the Minister to widen the door for young people to move permanently into aged care

The definitions of 'homeless' and 'at risk of homelessness' are not included in the Bill. The Minister can set and vary the definition by Regulation.

While the intent behind the inclusion of the exemptions to the age requirements is unclear, the move is likely to lead to perverse outcomes. The exemptions are proposed despite factors existing that should have convinced the Government to avoid exemptions for younger people at all costs, including:

- (i) the Aged Care and Disability Royal Commissions clearly stated that residential aged care is an **inappropriate setting** and service for people with disability under 65 years
- (ii) the selection of people who are First Nations, homeless and at risk of homelessness singles out these groups to receive different and less favourable treatment than other groups. For First Nations people especially, this raises the prospect of indirect discrimination on the basis of race and the risk of legal challenges

https://www.dss.gov.au/sites/default/files/documents/09 2020/dss younger people in residential aged care v5-1.pdf

Australian Institute of Health and Welfare (AIHW). (4 September 2024). Young people in residential aged care. Accessed on 25 September 2024 at <a href="https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care">https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care</a>

Summer Foundation. *Government YPIRAC targets not achieved*, 2 April 2023. Accessed on 25 November 2024 at <a href="https://www.summerfoundation.org.au/government-ypirac-targets-not-achieved/">https://www.summerfoundation.org.au/government-ypirac-targets-not-achieved/</a>

Department of Health and Aged Care (DoHAC). Australian Government response to the final report of the Royal Commission into Aged Care Quality and Safety. Accessed on 25 September 2024 at <a href="https://www.health.gov.au/resources/publications/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety">https://www.health.gov.au/resources/publications/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety</a>

(iii) **every person under 65 years** currently living in permanent residential aged care has a disability and **was 'homeless' or 'at risk of homelessness' when they entered**. A legislative instrument<sup>15</sup> made under the current *Aged Care Act* already requires that any younger person must meet both disability and housing insecurity conditions before they can be considered eligible for permanent residential aged care.

The Department's own guideline states:

To approve a younger person for access to permanent residential aged care, the Aged Care Act requires that there are no other care facilities or care services more appropriate to meet the person's needs (Section 6(1)(b) of the Approval of Care Recipient Principles refers). This is in addition to the overarching requirements specified in the Aged Care Act for all people seeking to access residential aged care.<sup>16</sup>

...

Residential Aged Care (RAC) is not designed to support younger people. The Government is committed to meeting its YPIRAC target that, except in exceptional circumstances, no people under 65 will be living in RAC by 2025. <sup>17</sup> (Emphasis added)

That is, notwithstanding that residential aged care is not appropriate for younger people, every younger person who was admitted to residential aged care met housing insecurity criteria (that is, there was no other accommodation option, or every other option was less appropriate) at the time they were admitted to the residential aged care facility. This is happening despite DoHAC acknowledging that residential aged care is not designed to support younger people and that young people should not live in residential aged care

- (iv) the overwhelming majority of younger people who have entered aged care over the last decade were 50-64 years old on admission<sup>18</sup>
- (v) more than **95% of younger people in permanent** residential aged care **are NDIS** participants<sup>3</sup>
- (vi) less than 10% of all exits from YPIRAC each year are accounted for by younger people transferring to live with 'family/home or other' 18
- (vii) the Department of Health and Aged Care (DoHAC) has provided **substantial funding** to provide navigators to assist YPIRAC who are not NDIS participants to transfer to

Federal Register of Legislation. *Approval of Care Recipients Principles 2014*, s6(1)(b). Accessed on 14 February 2024 at <a href="https://www.legislation.gov.au/F2014L00804/latest/text">https://www.legislation.gov.au/F2014L00804/latest/text</a>

Department of Health and Aged Care (DoHAC). *Principles and guidelines for a younger person's access to Commonwealth funded aged care services*, s3.1. Accessed on 25 September 2024 at <a href="https://www.health.gov.au/resources/publications/principles-and-guidelines-for-a-younger-persons-access-to-commonwealth-funded-aged-care-services?language=en">https://www.health.gov.au/resources/publications/principles-and-guidelines-for-a-younger-persons-access-to-commonwealth-funded-aged-care-services?language=en</a>

ibid., s3.3: 7. Accessed on 25 September 2024 at <a href="https://www.health.gov.au/resources/publications/principles-and-guidelines-for-a-younger-persons-access-to-commonwealth-funded-aged-care-services?language=en">https://www.health.gov.au/resources/publications/principles-and-guidelines-for-a-younger-persons-access-to-commonwealth-funded-aged-care-services?language=en</a>
Emphasis added.

Australian Institute of Health and Welfare (AIHW). Younger people in residential aged care. Accessed on 25 September 2024 at <a href="https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care">https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care</a>

live in the community<sup>19</sup>, however this has **resulted in less than 10 individuals leaving** residential aged care since 2021, and

(viii) **316** young disabled people who had no alternative accommodation **entered permanent** residential aged care **during 2022-23** (the last full year reported)<sup>20</sup>.

# 3. Institutionalises the substitution of aged care services for disability supports for young people with disability

The recent Aged Care and Disability Royal Commissions both separately made similar findings that the accommodation and services provided in residential aged care were unfit to meet the needs of young people with disability.

By formally approving young people to live in such facilities and receive aged care services, this Bill repudiates the recommendations of both Royal Commissions that the practice of placing young Australians with disability in residential aged care must stop.

### 4. Risks unintended financial hardship

In a complicated series of impacts, young people and their families can be financially imperilled by being forced to move into aged care.

When people become seriously disabled as adults (for example, people with progressive diseases like young onset dementia, Parkinson's disease and multiple sclerosis) they are often partnered and many have young children. If forced to move into residential aged care (this often happens after they are hospitalised because their care cannot be provided in their home) they are subject to the Aged Care means and assets tests as a member of a couple.

In addition, some disabled people are unable to access a Disability Support Pension because they are treated as an 'illness separated couple' and subject to the combined income and assets of both members of an illness separated couple.

As a result, the younger person in the nursing home may have no income and their spouse is required to fund substantial ongoing fees for their partner's care. In some cases, they may be forced to sell the family home to fund these costs. There are reports of committed couples who have divorced in order to avoid being treated as a couple for the purposes of the aged care assets and means tests.

## 5. Creates a default pathway from hospital

The pressure of 'bed block' in public hospitals has been cited as a direct cause of ambulance ramping and the deaths of people forced to wait for emergency medical

Department of Health and Aged Care (DoHAC). Younger people in residential aged care – Priorities for action.

Accessed on 25 September 2024 at <a href="https://www.health.gov.au/our-work/younger-people-in-residential-aged-care/priorities-for-action">https://www.health.gov.au/our-work/younger-people-in-residential-aged-care/priorities-for-action</a>

Australian Institute of Health and Welfare (AIHW). (2024) Younger People in Residential Aged Care. Accessed on 25 September 2024 at <a href="https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care">https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care</a>

care. The problem has been attributed largely to difficulties in discharging aged and disabled patients who are ready to leave.<sup>21</sup>

Many younger people with disability are unable to leave hospital because they have no suitable place to live – that is, they are homeless. By creating an option for young homeless disabled people without accommodation to be admitted to residential aged care, the Bill creates a formal pathway from hospital to nursing home. The Alliance is concerned that this will become the default pathway for young people with disability in these circumstances.

Indeed, the National Screening and Assessment Form (NSAF)<sup>22</sup> that provides an indication of 'inadequate housing' at the time of an aged care assessment classes 'inadequate housing' as:

- **Living in inadequate housing:** Such as sub-standard dwellings, poor sanitation, squalor, or unsafe/unsuitable housing for the person's level of functioning.
- With precarious tenure or who have imminent loss of ownership or accommodation rights: Where there is a likelihood of having to move because of increased rental and/or unsuitable accommodation that does not meet their needs.
- **Living in unstable housing:** Such as boarding and lodging, public housing, and staying with friends and/or relatives.
- Who are homeless: Those who do not have an acceptable roof over their head; are moving between various forms of temporary or medium term shelter such as hostels, refuges, boarding houses or friends; are constrained to living permanently in single rooms in private boarding houses and/or housed without conditions of home e.g. security, safety, or adequate standards (includes squatting). Homeless people have an increased risk of adverse health-related outcomes. Those having experienced long term homelessness are more likely to have risk factors such as alcohol and drug misuse and higher rates of mental and physical illness.

This is a very loose definition. If it is adopted as applying to s58 in the Bill, it increases the risk that hospitals under pressure will seek to invoke this definition in order to facilitate long stay patients who are young people with disability into residential aged care because they cannot return home.

It also provides no barrier for aged care entry for NDIS participants who may be relinquished by their support provider because of increasing need and lack of NDIS funding to support their changing needs. In the past, these participants have ended up in residential aged care. Under the Bill, this pathway will be formalised.

Department of Health and Aged Care. *National Screening and Assessment Form* (NSAF). Accessed on 25 September 2024 at <a href="https://www.health.gov.au/sites/default/files/documents/2019/12/my-aged-care-national-screening-and-assessment-form-fact-sheet">https://www.health.gov.au/sites/default/files/documents/2019/12/my-aged-care-national-screening-and-assessment-form-fact-sheet</a> 0.pdf

Australian Broadcasting Corporation. Ambulance ramping reaches 'crisis levels' as union casts doubt on improvements before next election, 24 July 2024. Accessed on 25 September 2024 at <a href="https://www.abc.net.au/news/2024-07-24/ambulance-ramping-crisis-levels-south-australia/104134834">https://www.abc.net.au/news/2024-07-24/ambulance-ramping-crisis-levels-south-australia/104134834</a>

Disability providers and advocates have expressed concern to the Alliance that this practice may increase if the NDIS Review's proposed 1:3 ratio of worker to participant in disability group homes is adopted. If this is the case, there is a real risk that a pipeline will be created from Supported Independent Living (SIL) services to residential aged care – something that the NSAF in its current form could facilitate.

### 6. Further discourages First Nations people from applying for NDIS

First Nations people with disability are often dissuaded from applying for access to the NDIS because of the administrative complexity and scarcity of services where they live.

By creating a legislated pathway to enter aged care without a requirement to test their eligibility for the NDIS, there is a risk that First Nations people aged 50-64 years will believe that aged care is the default option for them, and further discourage their application for access to the NDIS.

### 7. Normalises congregate aged care for young people

One of the key arguments for the establishment of the NDIS was to support a move away from congregate care for people with disability.<sup>23</sup>

By providing for a legislated pathway for younger people with disability to live in permanent residential aged care, the Bill 'normalises' aged care (that is, living in an institutionalised setting with a large number of older, frail people and receiving standardised aged care services) as an acceptable alternative to individualised disability support funded by the NDIS and provided in the community.

There is currently a tense debate underway within the Australian disability community about the future of one form of congregate care – group homes – as a supported living option<sup>24</sup>. The Disability Royal Commission noted the risks associated with group homes<sup>25</sup> and supported their phasing out. However, the Australian Government has stated that the recommendation needs 'further investigation'<sup>26</sup> and the NDIA has not changed its approach to group homes<sup>27</sup>.

Congregate care in the context of disability in Australia refers to residential settings where multiple individuals with significant disability live together in larger numbers to receive care and support services. In the past, the most common settings were institutionalised large residential centres, nursing homes, and large group homes. The NDIS was designed to move away from these kinds of care and towards individualised arrangements. The primary characteristic of congregate care is that it involves shared living spaces, communal care and reduced choice and control. The alternative is independent living arrangements, individualised care, and choice and control by the individual.

Sydney Morning Herald. The old institutions are gone, but the segregation debate has a long way to go. 29 September 2023. Accessed on 25 September 2024 at <a href="https://www.smh.com.au/politics/federal/the-old-institutions-are-gone-but-the-segregation-debate-has-a-long-way-to-go-20230928-p5e8cn.html">https://www.smh.com.au/politics/federal/the-old-institutions-are-gone-but-the-segregation-debate-has-a-long-way-to-go-20230928-p5e8cn.html</a>

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Issues Paper – Group Homes, November 2019. Accessed on 25 September 2024 at <a href="https://disability.royalcommission.gov.au/system/files/2022-03/lssues%20paper%20-%20Group%20homes.docx">https://disability.royalcommission.gov.au/system/files/2022-03/lssues%20paper%20-%20Group%20homes.docx</a>

Special Broadcasting Service (SBS). Disability rights groups 'devastated' by government's Royal Commission response, 31 July 2024. Accessed on 25 September 2024 at <a href="https://www.sbs.com.au/news/article/disability-rights-groups-devastated-by-governments-royal-commission-response/zgxv490j3">https://www.sbs.com.au/news/article/disability-rights-groups-devastated-by-governments-royal-commission-response/zgxv490j3</a>

National Disability Insurance Scheme (NDIS). Home and Living, 20 February 2024. Accessed on 25 September 2024 at <a href="https://www.ndis.gov.au/participants/home-and-living">https://www.ndis.gov.au/participants/home-and-living</a>

This is complicated by the commentary by the NDIS Review which appeared to suggest that there should be a default ratio of staff to participants in SIL group homes of 1:3, a ratio which would not meet the needs of many participants.

### 8. Allows cost shifting

The care of young people with disability living as aged care clients in permanent residential aged care is cheaper for the NDIA than if these same individuals were living in the community.

By creating a right of access to aged care services, the Bill allows the NDIA to avoid funding the reasonable and necessary supports needed by these individuals.

The Bill also absolves state and territory governments from funding the care of young people who are not NDIS participants. Currently fewer than 5% of young people in permanent residential aged care are ineligible for the NDIS. This small group currently includes:

- people with disability created by life limiting conditions (for example, brain or other cancers) whose application to access the NDIS has been delayed
- those with severe disability who do not meet residency requirements for access to the NDIS (that is, non-residents)
- First Nations people with significant disability who have not applied for the NDIS, and
- those with temporary disability (often caused by acute health problems including temporary blindness, alcohol and drug disorders, orthopaedic or other conditions awaiting surgery) who do not meet the permanency requirements for access to the NDIS.

### 9. Reduces aged care services available for older Australians

Every young person who becomes an aged care client takes away resources that should be allocated to an older Australian.

By taking an aged care bed (that is, a service funded by the aged care system), funding is diverted away from older Australians.

### 10. Fundamentally weakens the aged care safeguarding framework

The Aged Care Royal Commission recommended a statutory duty of care for aged care providers. The *Exposure Draft of the Aged Care Bill* contained criminal and civil penalties for providers guilty of serious breaches of their duty of care, as well as provisions for compensation for users of aged care services who suffer harm as a result.

The criminal sanctions for breaches of provider duty of care have been removed from this Bill, leaving only civil penalties for providers.

The Aged Care Royal Commission's recommended duty of care mirrored the provisions in Work Health and Safety (WHS). As currently drafted, the *Aged Care Bill* will result in providers facing lesser penalties for breaches of their duty of care to their clients and residents than they face in relation to their workers under the WHS legislative framework.

Boards and management of aged care services already face criminal liability for harm done to workers and clients under the WHS regime. The argument that including criminal liability will discourage people from joining aged care provider boards or working in aged care is, therefore, misplaced as these penalties already exist for serious occupational safety breaches.

## **Conclusion**

The Aged Care Bill 2024 provides the opportunity to draw a line in the sand and end the discredited practice of forcing young people with disability to become aged care clients in order to access required supports.

We urge the Committee to make recommendations that avoid the Commonwealth undermining its own longstanding policy on ending young people being forced to receive aged care services as a replacement for disability supports.

Adding a requirement to s58 for young people to test their eligibility for the NDIS before they enter aged care will protect those who the Bill ostensibly seeks to assist – that is, people who are First Nations, homeless, or at risk of homelessness - from discrimination.

It will also shine a spotlight on the NDIS and its responsibility to ensure that young people with disability get the supports to which they are entitled and need to live a safe and dignified life.

All people with disability need the genuine choice of where they live and how they are supported, and our recommendations would help this become real - rather than illusory - for people facing aged care placement.

For those young people who do end up in residential aged care – and the older Australians with whom they will share their accommodation – the Alliance also urges the Committee to recommend the restoration of criminal sanctions for serious breaches of provider duty of care.

The Parliament must be alert to the opportunity presented here to end a practice which successive governments have agreed is wrong and should stop.

#### **Further contact**

Steven Davison
Director, Government and Stakeholder Relations

### **Endorsements**

This submission has been endorsed by the following Disability Representative and Carer Organisations (DRCO).







