

# Submission to Aged Care Bill 2024 [Provisions]

30 September 2024

Committee Secretary  
Senate Standing Committees on Community Affairs  
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The Australian Autism Alliance (Autism Alliance) is focussed on Autistic people and their families and has strong interests in matters that affect Aged Care. The Autism Alliance welcomes the opportunity to provide this submission to the Senate Standing Committee inquiry into the Aged Care Bill 2024.

## About the Australian Autism Alliance

[www.australianautismalliance.org.au](http://www.australianautismalliance.org.au)

The Autism Alliance aims to provide 'One United Voice for Autism'. The Autism Alliance was established in 2016 and aims to improve the life chances of autistic people and facilitate collaboration within the autism community. As of 1st July 2024, the Autism Alliance is a funded Disability Representative Organisation. The members represent a cohesive national network of key organisations with a diverse focus on autism – that is led by autistic people, advocacy groups, peak bodies, service providers, and researchers. We reach over half a million people through our communication channels and provide support to people with autism across the lifespan. Most importantly, our work is informed by autistic people and their families and carers.



## Acknowledgment:

We acknowledge the First Nations and Traditional Owners of the land, sea and waterways and pay respects to Elders past, present and recognise those whose ongoing effort to protect and promote Aboriginal and Torres Strait Islander cultures will leave a lasting legacy for future Elders and leaders.

We recognise and thank emphatically all the Autistic and disabled people who contributed to this unique perspective for the purpose of learning and growing together to achieve better outcomes for all.

### Summary of Recommendations:

- **Recommendation 1:** Include a Commitment in the Aged Care Bill to Develop and Implement a Strategy for Autistic people in aged care.
- **Recommendation 2:** Government endorsement and funding for the development of a framework for safeguarding and maintaining long-term care of Autistic people (legal and other formal arrangements) to ensure succession of care planning. This should include the development and implementation of succession of care disability standards and build capacity and capability to create and administer succession case plans. This also needs to make reference to a supported decision making protocol.
- **Recommendation 3:** A section regarding communications is captured in the Aged Care Bill to outline reference to a co-design protocol, and communication framework that supports the diversity, rights, and autonomy of Autistic people who have complex communication needs (CCN). Items identified are:
  - identification of CCN subgroups
  - the range of communication devices and methods that Autistic people use
  - supported decision making
- **Recommendation 4:** Implement an autism core capabilities framework to identify key capabilities for those working with and for supporting Autistic people including those requiring very high supports and dependency needs:
  - values and behaviours that underpin all the capabilities in the framework.
  - evaluation methodology:
    - individual assessment of knowledge and/or competence
    - impact on practice
    - impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
  - continuous monitoring and annual reporting requirements.
  - built-in timelines for review of the framework (every 3 years)
- **Recommendation 5:** Section 58 of the Bill should be amended to limit aged care access for people under 65 years to only those aged 50-64 years who are not eligible for the NDIS, as follows:
 

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; and
  - (b) information of a kind prescribed by the rules has been provided relating to the individual's care needs; and
  - (c) if the individual is aged less than 65, the individual:
    - (i) has elected, in the approved form, to be provided with funded aged care services before the individual turns 65; and
    - (ii) was informed, prior to making the election, of any other services that may be available to meet the care needs of the individual
- **Recommendation 6:** 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. This arrangement for people living in residential aged care but not as aged care clients and who receive no aged care funding, should be recognised in the Bill and associated regulatory system.
- **Recommendation 7:** 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.

## Detail

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, however, have a number of specific recommendations to improve the outcomes for Autistic people specifically and three specific areas of concerns.

### Outcomes for Older Autistic People

It was recognised in the Senate Select Committee on Autism<sup>1</sup> with outcomes manifestly worse for Autistic people than for people with disability more generally, urgent and dedicated action is needed. This includes relating to Aged Care.

While all Autistic people face the prospects of a lower life expectancy than the general population, the current older generations of Autistic people are at risk of dying even more prematurely due to factors such as lack of access to supports and a reliance on large institutional environments; where it is more common for people to die prematurely.<sup>2</sup>

### Relevant Intersectionality Issues

For older people who experience intersectional disadvantage, there are a number of compounding issues which impact their experience. For example, older Autistic women who live in aged care facilities are much more likely than males to experience sexual harassment and violence. While statistics on the rates of sexual violence experienced by older Autistic women do not exist, reports on the issue of sexual violence in aged care facilities have indicated that residents with cognitive disabilities are at higher risk.<sup>3</sup> Additionally, the tendency of older Autistic women to miss social cues, experience communication difficulties and have few family and friends to report issues, makes them a target for violence in the aged care system.

The NDIS is the only national support system tailored to Autistic and disabled people, but currently, people over 65 years are not eligible.

Like all other areas, there is a desperate need for aged care staff to be equipped to support older Autistic people. While many of the qualifications required to become an aged carer are lumped in disability support work qualifications, the majority of these courses are not specific enough to equip individuals to support specific disabilities, and the content is not consistent across providers.<sup>4</sup>

Additionally, in recent years, it has been identified that there is a need to better equip aged care staff and facilities to recognise and respond to instances of poor treatment, neglect, and violence. While the Aged Care Quality and Safety Commission include the remit to investigate and act on instances of violence, abuse, neglect, and poor treatment in aged care facilities through the Serious Incident Response Scheme (SIRS),<sup>5</sup> current guidelines first require aged

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<sup>1</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [v].

<sup>2</sup> Ibid, p. 12

<sup>3</sup> See for example Knaus, C (2022) 'Shocking' rate of sexual abuse of aged care residents barely changed since royal commission,' *Guardian*, Viewed 12 June 2023 <<https://www.theguardian.com/australia-news/2022/jun/06/shocking-rate-of-sexual-abuse-against-aged-care-residents-barely-changed-since-royal-commission>>.

<sup>4</sup> See for example: Autism Awareness Australia (2021) 'Beyond School: Further education,' Viewed 13 June 2023 <<https://www.autismawareness.com.au/beyond-school/further-education>>.

<sup>5</sup> Aged Care Quality and Safety Commission (2023) 'Serious Incident Response Scheme: Frequently Asked Questions,' Viewed 13 June 2023 <<https://www.agedcarequality.gov.au/sirs/frequently-asked-questions>>.

care facilities to report an incident within 24 hours and to determine if there is an impact on the victim.<sup>6</sup>

Given that most aged care staff are not trained in recognising and responding to abuse and violence, and that the majority of aged care facilities are battling with stretched human resources, these requirements place impossible standards on individuals.

**Recommendation 1:** Include a Commitment in the Aged Care Bill to Develop and Implement a Strategy for Autistic people in aged care.

### Succession Care

There is very little legislation, policies or framework regarding succession care or capability and capacity of organisations to create and administer, particularly for Autistic people requiring very high support and dependency needs.

*“The legal aspects of care of autistics persons needing care to manage their lives beyond the lifetime of their family members/parents has always been of great concern”.*

*“financial management and effective guardianship safeguarding an autistic person's financial and other safety is an area that needs special attention”*

*“There is a need to find safer alternatives to being under guardianship trustee “*

*“Resourcing and enforcing supported decision making also need to be receive mention”*

**Recommendation 2:** Government endorsement and funding for the development of a framework for safeguarding and maintaining long-term care of Autistic people (legal and other formal arrangements) to ensure succession of care planning. This should include the development and implementation of succession of care disability standards and build capacity and capability to create and administer succession case plans. This also needs to make reference to a supported decision making protocol.

### Complex Communication Needs

It was highlighted in feedback that the diverse communication styles of Autistic people are often overlooked and needs to be recognised and accommodated. This includes how people receive information and how they communicate themselves. It was also emphasised that communication methods need to be the choice of the individual to suit their preferences and needs. This could be through assistive technologies, visual aids, or alternative communication techniques.

*“I would like the needs of non-speakers like me and people with apraxia receive special consideration as we have severe disadvantages. I see independence as a goal that I have to reach to live a good life. In order for people with CCN to have a positive life big change with a long term strong commitment needs to be incorporated. Many of us with CCN have shown that we have skills such as literacy. This has not been acknowledged by service providers. Many of us are limited to a life of dependency due to ‘presumption of incompetence”.*

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<sup>6</sup> See for example: Alderslade, L (2022) ‘Recent data shows over 500 sexual assaults in aged care in three months,’ *Aged Care Guide*, Viewed 13 June 2023 <<https://www.agedcareguide.com.au/talking-aged-care/recent-data-shows-over-500-sexual-assaults-in-aged-care-in-three-months>>.

Supported decision making also needs to be recognised:

*“Supported Decision Making is more about respecting the individual and having consistent (not ever changing) supports that can learn to translate their clients preferences and needs through the intimacy of their understanding of minor cues - it's also about training and creating manuals etc that support new workers in understanding them etc. It is the only alternative communication for many”.*

**Recommendation 3:** A section regarding communications is captured in the Aged Care Bill to outline reference to a co-design protocol, and communication framework that supports the diversity, rights, and autonomy of Autistic people who have complex communication needs (CCN). Items identified are:

- a. identification of CCN subgroups
- b. the range of communication devices and methods that Autistic people use
- c. supported decision making

### Autism Core Capabilities Framework

Inappropriate and unskilled care for Autistic individuals can put health at serious risk, cause unnecessary restrictive practices like over medication and restraints, and lasting mental trauma. These experiences seem to occur predominately with Autistic people and in particular those with very high support and dependency needs.

*“You are allowed to have strong emotions and not be seen as a crazy person, but when you speak to a psychiatrist you know you withhold those strong emotions”.*

High-quality information and training are a key enabler for implementation. An example is the UK has developed a national autism core capabilities framework<sup>7</sup> to identify key capabilities for those working with and for supporting Autistic people. A tiered approach is used: Tier 1 for those who require a general understanding of autism but may not regularly work for Autistic people; Tier 2 for those who provide care and support for Autistic people but are not autism specialists; Tier 3 for those who work intensively with Autistic people.

**Recommendation 4:** Implement an autism core capabilities framework to identify key capabilities for those working with and for supporting Autistic people including those requiring very high supports and dependency needs:

- values and behaviours that underpin all the capabilities in the framework.
- evaluation methodology:
  - individual assessment of knowledge and/or competence
  - impact on practice
  - impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
- continuous monitoring and annual reporting requirements.
- built-in timelines for review of the framework (every 3 years).

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<sup>7</sup> [https://www.autismhampshire.org.uk/assets/uploads/Autism\\_Capabilities\\_Framework\\_Oct\\_2019\\_1.pdf](https://www.autismhampshire.org.uk/assets/uploads/Autism_Capabilities_Framework_Oct_2019_1.pdf)

## Eligibility Provisions for People Aged Under 65 Years

The Aged Care Bill 2024 has introduced for the first time a legislated age criteria and legislated exemptions 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. The Bill requires that people in this group who are approved for residential aged care must be assessed as having high support needs (that is, be disabled).

There are significant concerns regarding this introduction as it is an astounding reversal of the longstanding bipartisan Australian Government policy of no young people living in residential aged care.

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. This would have required a plan to be successfully implemented that anticipated and responded to the needs of young people living in residential aged care, which 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 – by younger people dying in aged care or ageing out of the YPIRAC cohort and no longer being counted.

Hence the allowing of young people into residential aged care is deeply concerning. This commonly recognised stop gap should not be legislated.

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>8</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.

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<sup>8</sup> 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 <https://www.health.gov.au/resources/publications/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety>

To date the statistics, show that this move is likely to lead to perverse outcomes. 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<sup>9</sup> reveals that:

- there are over 1500 people living in permanent residential aged care who entered as young people but who are now aged over 65 years.
- 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.
- the overwhelming majority of younger people who have entered aged care over the last decade were 50-64 years old on admission.<sup>10</sup>
- more than 95% of younger people in permanent residential aged care are NDIS participants<sup>23</sup>
- less than 10% of all exits from YPIRAC each year are accounted for by younger people transferring to live with 'family/home or other'<sup>11</sup>

The factors existing that should have convinced the Government to avoid exemptions for younger people, include:

- (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. 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.
- (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. 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.
- (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. Delegated legislation<sup>12</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

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<sup>9</sup> 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-aged-care>

<sup>10</sup> Australian Institute of Health and Welfare (AIHW). *Younger people in residential aged care*. Accessed on 14 February 2024 at <https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care>

<sup>11</sup> Australian Institute of Health and Welfare (AIHW). *Younger people in residential aged care*. Accessed on 25 September 2024 at <https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care>

<sup>12</sup> Federal Register of Legislation. *Approval of Care Recipients Principles 2014*, s6(1)(b). Accessed on 14 February 2024 at <https://www.legislation.gov.au/F2014L00804/latest/text>

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>13</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>14</sup>

- (iii) 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 live in the community<sup>15</sup> which has resulted in less than 10 individuals leaving residential aged care since 2021, and 316 young disabled people who had no alternative accommodation entered permanent residential aged care during 2022-23 (the last full year reported)<sup>16</sup>.
- (iv) 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 (often after they are hospitalised because their care cannot be provided in their home) they are subject to means and assets tests as a member of a couple for the purposes of the costs of their care. 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, spouses are often required to fund substantial ongoing fees for their partner's care in the nursing home and, in some cases, sell the family home to fund these costs. There are reports of committed couples who have been forced to divorce in order to avoid being treated as a couple for the purposes of aged care costs.
- (v) this will become the default pathway from hospital for young people with disability in these circumstances. The pressure of 'bed block' in public hospitals has been cited as

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<sup>13</sup> 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 <https://www.health.gov.au/resources/publications/principles-and-guidelines-for-a-younger-persons-access-to-commonwealth-funded-aged-care-services?language=en>

<sup>14</sup> *ibid.*, s3.3: 7. Accessed on 14 February 2024 at <https://www.health.gov.au/resources/publications/principles-and-guidelines-for-a-younger-persons-access-to-commonwealth-funded-aged-care-services?language=en>  
Emphasis added.

<sup>15</sup> Department of Health and Aged Care (DoHAC). *Younger people in residential aged care – Priorities for action*. Accessed on 25 September 2024 at <https://www.health.gov.au/our-work/younger-people-in-residential-aged-care/priorities-for-action>

<sup>16</sup> Australian Institute of Health and Welfare (AIHW). (2024) *Younger People in Residential Aged Care*. Accessed on 25 September 2024 at <https://www.gen-agedcaredata.gov.au/resources/younger-people-in-residential-aged-care>

a direct cause of ambulance ramping and the deaths of people forced to wait for emergency medical care.

The problem has been attributed largely to difficulties in discharging aged and disabled patients who are ready to leave.<sup>17</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. That is, 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.

- (vi) 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. This practice may increase if the proposed 1:3 funding limits in disability residential services proposed by the NDIS review are 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 National Screening and Assessment Form (NSAF) in its current form could facilitate.
- (vii) this 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>18</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 standard aged care services) as an acceptable alternative to 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>19</sup>. The Disability Royal Commission noted the risks associated with group homes<sup>20</sup> and supported their phasing out. However, in response, the Australian Government has stated that the

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<sup>17</sup> 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 <https://www.abc.net.au/news/2024-07-24/ambulance-ramping-crisis-levels-south-australia/104134834>

<sup>18</sup> Congregate care in the context of disability in Australia refers to residential settings where multiple individuals with disabilities live together and receive care and support services. These settings can include group homes, nursing homes, and other institutional environments. The primary characteristic of congregate care is that it involves shared living spaces and communal care, as opposed to individualized or independent living arrangements.

<sup>19</sup> 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 <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>

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

recommendation needs 'further investigation'<sup>21</sup> and the NDIA has not changed its approach to group homes<sup>22</sup>.

(viii) this will allow for 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. 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 their basic care costs (Basic Care Subsidy and Accommodation Supplement) and the NDIA annually reimburses DoHAC via a 'cross-billing' arrangement for these costs. There is no specific provision in the NDIS Act that allows for this 'cross-billing' arrangement. Other costs are charged to the participant subject to the means and assets tests, some of which the participant may get NDIS funding for in their plan, however there is little transparency about who gets what funding across the YPIRAC cohort. This cross-billing arrangement for funding of aged care services for NDIS participants substitutes aged care services for disability supports and effectively outsources the obligations of the NDIS CEO to determine 'reasonable and necessary' supports to the Aged Care system. 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. 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 not eligible for the NDIS. This small group 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.

(ix) this 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), this diverts aged care funding away from older Australians.

**Recommendation 5:** Section 58 of the Bill should be amended to limit aged care access for people under 65 years to only those aged 50-64 years who are not eligible for the NDIS, as follows:

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<sup>21</sup> Special Broadcasting Service (SBS). Disability rights groups 'devastated' by government's Royal Commission response, 31 July 2024. Accessed on 25 September 2024 at <https://www.sbs.com.au/news/article/disability-rights-groups-devastated-by-governments-royal-commission-response/zgxv490j3>

<sup>22</sup> National Disability Insurance Scheme (NDIS). Home and Living, 20 February 2024. Accessed on 25 September 2024 at <https://www.ndis.gov.au/participants/home-and-living>

### **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; and*
- (b) *information of a kind prescribed by the rules has been provided relating to the individual's care needs; and*
- (c) *if the individual is aged less than 65, the individual:*
- (i) *has elected, in the approved form, to be provided with funded aged care services before the individual turns 65; and*
  - (ii) *was informed, prior to making the election, of any other services that may be available to meet the care needs of the individual.*

Over 95% of young people who are living in permanent residential aged care are NDIS participants.<sup>23</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 a 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 care system.

For those young people with significant disability living in, or at risk of entering, residential aged care who are not eligible for the NDIS because they do not meet the residency or disability criteria (less than 5% of current residents), Australian Governments should agree on who should fund their care and how it should be provided. 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),

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<sup>23</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 <https://www.gen-agedcaredata.gov.au/getmedia/d0891861-2d52-4738-b6c4-6bc7aa9eb9d1/YPIRAC-Dec-2023-Factsheet%281%29.pdf>. 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 <https://www.ndis.gov.au/media/6468/download?attachment>. Total number of participants (including First Nations participants) in permanent residential aged care on 30 September 2023 was 1595.

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.

**Recommendation 6:** 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. This arrangement for people living in residential aged care but not as aged care clients and who receive no aged care funding, should be recognised in the Bill and associated regulatory system.

### **Weakening of the 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 that of the work health and safety legislation. As currently drafted, the provisions in this Bill mean providers will face lesser penalties for breaches of their duty of care to their clients and residents than they face in relation to their workers under the Work Health and Safety (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 work in aged care is, therefore, misplaced as these penalties already exist for serious occupational safety breaches.

In order to protect those 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.

**Recommendation 7:** 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.

We strongly urge the above recommendations be adopted to ensure that people with disability, including Autistic Australians get the supports to which they are entitled and need to live a safe and dignified life. People with disability need the genuine choice of where they live and how they are supported.

We thank you for the opportunity to respond and are committed to working with the Australian Government to achieve all people with disability, including Autistic people, thriving in an effective and inclusive eco system.

Please do not hesitate to contact us with any queries or requests for further information.

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