



**Response to the
Aged Care Bill 2023 Exposure Draft**

February 2024



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

Please direct any enquiries about this report to:

Samantha Fox
Chief Executive Officer
Phone: (03) 6144 3700
Email: [REDACTED]

Contents

1. Background.....	4
2. Introduction	5
3. Recommendations	6
No further delay in progression of the Act.....	6
Review timeline	6
Human rights, wellbeing, and choice and control	6
Suggested amendments to the definitions	7
Amendment to the Complaints Process.....	8
Timely access to support.....	8
Carer recognition.....	10
A stronger disability focus.....	12
Clear eligibility guidelines for early access to aged care services	12
Advocacy, information, and navigation services	13
The diverse needs of older Australians.....	14
Restrictive practices	14
Supporters and representatives.....	15
Whistleblower protections.....	16
Undrafted sections of the Bill	17
Recommendations.....	17

1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Australian Government Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania is pleased to respond to the Aged Care Bill Exposure Draft (the Exposure Draft).¹ The Exposure Draft is intended to replace the current *Aged Care Act 1997* (Cth)² and the *Aged Care Quality and Safety Commission Act 2018* (Cth).³ The new Act is intended to take a more person-centred approach to the wellbeing of older people, in comparison to the *Aged Care Act* (Cth) which is primarily focussed on provider regulation and payment. The Exposure Draft provides a more person-centred, human-rights based approach to aged care, whilst including stronger regulatory powers to help increase the safety of older Australians.

In the information available on the Exposure Draft, it was noted that the Department is interested to hear thoughts about:

- *Whether the reform timetable needs to be adjusted, noting the proposal for the new Act to commence on 1 July 2024*
- *The operation of draft provisions included in the Exposure Draft and what is proposed for the Aged Care Rules (the Rules)*
- *Whether the draft provisions give effect to the policy intent and the Royal Commission's vision for the future of aged care*
- *How we have responded to feedback received to date on proposed inclusions in the new Act, and*
- *The intent for parts of the Bill still being drafted, as explained in this consultation paper.*⁴

Our response addresses several of these items and in conjunction, supports the preliminary recommendations outlined in the Key Issues Paper⁵ prepared by COTA Australia, OPAN, Carers Australia, and several other national organisations who advocate for older Australians and their carers.

¹ Australian Government Department of Health and Aged Care. (2023). *Aged Care Bill Exposure Draft 2023* (Cth). Available from: <https://www.health.gov.au/sites/default/files/2023-12/exposure-draft-aged-care-bill-2023.pdf>

² Aged Care Act 1997 (Cth). Available from <https://www.legislation.gov.au/C2004A05206/latest/text>

³ Aged Care Quality and Safety Commission Act 2018 (Cth). Available from: <https://www.legislation.gov.au/C2018A00149/latest/text>

⁴ Australian Government Department of Health and Aged Care. (2023). *Aged Care Bill Exposure Draft, Consultation Paper No.2, 2023*. Available from: <https://www.health.gov.au/sites/default/files/2024-02/a-new-aged-care-act-exposure-draft-consultation-paper-no-2.pdf>

⁵ OPAN and COTA. (2024). *Aged Care Act Exposure Draft; Key Issues Paper*. Available from: <https://cota.org.au/wp-content/uploads/2024/01/Aged-Care-Act-Exposure-Draft-%E2%80%93-Key-Issues-Paper-Jan-24-FINAL.pdf>

3. Recommendations

No further delay in progression of the Act

Timely progression of this legislation is crucial, and it must not be delayed any further. The Aged Care Royal Commission Final Report was tabled in Parliament on 1 March 2021. Recommendation One states: “*The Aged Care Act 1997 (Cth) should be replaced with a new Act to come into force by no later than 1 July 2023.*”⁶ Whilst the comprehensive nature of this legislation must be acknowledged, the Act must not be delayed past 1 July 2024. The longer implementation takes, the risk of older Australians not receiving the high quality, person-centred support they deserve is heightened. In the meantime, carers, often to their own detriment, continue to provide the supports that are not being provided by Government and Government funded services.

Review timeline

The current Exposure Draft proposes that an independent review of the Act must be conducted within six months of the fifth anniversary of its commencement. We recommend this Act be reviewed at the three-year mark. A five-year review period is too long for a new piece of legislation, especially one that is so complex and important. A three-year review period is a more suitable timeframe to ensure that appropriate implementation of any amendments can occur as early as possible. This will help ensure this legislation will effectively meet the needs of older Australians and will remain fit-for-purpose.

Human rights, wellbeing, and choice and control

It is pleasing to observe that the legislation takes a strong focus on the provision of high-quality care and upholding choice and control as key components to help ensure that supports are person-centred, not delivered just for the financial benefit of businesses.

The Aged Care Royal Commission uncovered far too many situations in which older Australians did not receive support that upheld their human rights, their dignity, and personal wellbeing. Rather, older Australians have been let down. They and their families and carers have not always had a say in what supports were most needed, when, and how they should be delivered.

The Exposure Draft specifies:

Section 5

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

In principle, this is laudable, but to ensure providers have the ability to deliver a truly flexible, person-centred, responsive service, they must be equipped to do so. The Australian Government must also commit to support these services to deliver on this legislative requirement, which in turn will lead to better outcomes for older Australians who need support, as well as their carers.

⁶ Commonwealth of Australia. (2021). *Royal Commission into Aged Care Quality and Safety. Final Report Volume 1*. <https://www.royalcommission.gov.au/system/files/2021-03/final-report-recommendations.pdf>

The Exposure Draft appears to focus on the deficit-based needs of older Australians. For example, the Exposure Draft frequently uses words such as a sickness, and ill health. To really provide high-quality care that is person-centred, the legislation must ensure there is also a focus on upholding the positive aspects of a person's life.

The Exposure Draft describes the meaning of high-quality care. The items listed within this description should be standard across providers, rather than 'top of the range' services. The aspects should be the underlying standard of care delivered by all providers, as these items correlate with the Statement of Rights and Statement of Principles.

Suggested amendments to the definitions

Carers Tasmania proposes some amendments to the definitions specified within the Exposure Draft.

For example, *serious injury or illness of an individual means an injury or illness requiring the individual to have:*

- (a) immediate treatment as an in-patient in a hospital; or*
- (b) immediate treatment for:*
 - (i) the amputation of any part of the individual's body; or*
 - (ii) a serious head injury; or*
 - (iii) a serious eye injury; or*
 - (iv) a serious burn; or*
 - (v) the separation of the individual's skin from an underlying tissue (such as degloving or scalping); or*
 - (vi) a spinal injury; or*
 - (vii) the loss of a bodily function; or*
 - (viii) serious lacerations; or*
- (c) medical treatment within 48 hours of exposure to a substance; and includes any other injury or illness prescribed by the rules but does not include an illness or injury of a kind prescribed by the rules.⁷*

We seek for the inclusion of serious psychological distress within this definition.

The definitions section also states:

- (2) A residential care home means a place that:*
 - (a) is the place of residence of individuals who, by reason of sickness, have a continuing need for aged care services, including nursing services; and*
 - (b) is fitted, furnished and staffed for the purpose of providing those services.*
- sickness means an infirmity, illness, disease, incapacity or impairment.⁸*

⁷ Aged Care Bill Exposure Draft 2023 (Cth). Available from: <https://www.health.gov.au/sites/default/files/2023-12/exposure-draft-aged-care-bill-2023.pdf>

⁸ Ibid.

We recommend the use of clearer language in this section, for example, specifying sickness, disability, and ageing. Despite infirmity broadly covering disability and ageing, it needs to be clear so that those in the community understand that this legislation is there to support them. The use of the term infirmity is deficit-based and reinforces a negative idea of people who use residential aged care facilities.

Amendment to the Complaints Process

Carers Tasmania supports the recommendations outlined in the Key Issues Paper⁹ regarding the need for further amendment to the complaints process, and that in addition, the Complaints Commissioner should have direct independent statutory authority and functions. The Complaints Framework should also be reflected within the Act for greater legislative protections and oversight. This will ensure that the Complaints Framework cannot be altered without following the appropriate legislative pathway.

Timely access to support

As of 30 September 2023, there were 41,950 older people across Australia waiting in the National Priority System (NPS) for a home care package (HCP) at their approved level. Within the same period of time, a significant number of people (32,063) who were waiting for a home care package did not have an interim home support in place. There could be many reasons for this, however, if people have been assessed for a home care package, it is evident that they need some level of support and should not go without until an appropriate package is available. They must be connected to interim supports, and if there is a carer, they must also be referred to Carer Gateway so they can access support and information within their own right.

The GEN data stated that the estimated wait time for package approval (not commencement) for people entering the NPS on 31 October 2023 was:

HCP level	Time to approve HCP
Level 1	Less than 1 month
Level 2	3 to 6 months
Level 3	6 to 9 months
Level 4	1 to 3 months

The Act must specify appropriate timeframes for service access. This means including not just a timeframe for assessment to occur, but appropriate timeframes for services to begin. We know that people often wait far too long before their support commences, and these wait times vary depending on complexity of support required and geographical locations. This can result in injury to both older people and those they provide care for, as well as carer burnout, social isolation, and financial disadvantage. In some cases, older people pass away before they receive the support they need. The reality is, that in some parts of Australia, there are few or no service providers to provide the support that's needed. Older people may be approved for a package, and there may be several providers who state that they service any given area, but there may be long wait times before they receive the support. All older

⁹ OPAN and COTA. (2024). *Aged Care Act Exposure Draft; Key Issues Paper*. Available from: <https://cota.org.au/wp-content/uploads/2024/01/Aged-Care-Act-Exposure-Draft-%E2%80%93-Key-Issues-Paper-Jan-24-FINAL.pdf>

people who need it must be able to access appropriate aged care support regardless of where they live.

Carer case study:

This story has been de-identified for privacy. We share this story to urge consideration of how service access can be improved to ensure equitable access to support when needed.

Mrs. A contacted Care2Serve in early 2023. Her husband, Mr. B had initially been assessed for a home care package (HCP) in 2021. After the assessment, Mrs. A and Mr. B contacted more than 10 providers, none of whom were able to take on the HCP due to their location. This was in the North-West of Tasmania, just less than a 40-minute drive from the city of Burnie.

Mr B. was diagnosed with a terminal condition, which affected his mobility and capacity to complete his own personal care. His support needs began to increase, leading to an aged care reassessment in February 2023. During the assessment, the assessor informed them that Mr. B should have been assigned a level 4 HCP in 2021. Unfortunately, Mr. B was terminally ill at this point and passed away soon after in March 2023. No support was received through a HCP at any point and other supports were not engaged. This was a terrible experience for Mrs. A and Mr. B, which resulted in them struggling significantly each day to get by in the last years of Mr. B's life.

We support the proposed solution in the Key Issues Paper, suggesting that the Act should include a legislative requirement whereby the System Governor must provide a public report on a quarterly basis on the wait times from application through to the assessment, and from assessment to when service delivery begins. The NDIS has a Participant Service Guarantee that outlines specific timeframes for different aspects of accessing the scheme. The NDIA also reports each quarter on their progress against meeting the timeframes set out in this guarantee.¹⁰ Adopting an approach such as this would support the following recommendations from the Royal Commission into Aged Care:

- i. older people should have certainty that they will receive timely high-quality support and care in accordance with assessed need,*
- ii. informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need.*

In addition to the provision of support for older people at home, Carers Tasmania believes that this legislation should better support those needing to access an aged care facility. Although residential aged care facilities directly assist older people, they offer respite to carers so they can have a break, rest, and recover. From a Tasmanian perspective, there are generally long wait times to access respite in residential aged care facilities, even in emergency situations, and especially for those needing dementia secure units. This is a longstanding issue. Despite reform occurring for carer supports transitioning from Commonwealth Respite and Carelink Centres (CRCC) to Carer Gateway, the processes to access residential respite bookings vary between the states and territories.

¹⁰ NDIS. (2023). Participant Service Guarantee. Available from: <https://www.ndis.gov.au/about-us/policies/service-charter/participant-service-guarantee>

Some facilities and regions have waitlists of several months, making emergency respite in aged care facilities near impossible.¹¹ Care2Serve's Residential Respite Booking Officers report that they often struggle to find suitable respite when requested, due to the low number of respite beds available at any given time. They have also been informed by some facilities that they will only take clients for respite if they are planning on transitioning to a permanent resident of the facility. This leaves carers frustrated, burnt out and negatively impacts their wellbeing, which, over time can diminish their capacity to provide care.

The 2022 National Carer Survey reported that the five most frequently identified issues when trying to support someone accessing aged care services were:

- *The services were reduced or interrupted due to COVID-19 (40.4%)*
- *There was a long waiting period to access services (39.4%)*
- *It was difficult to find information about what services were available and how to access them (33.6%)*
- *There was a long waiting period to get assessed (32.9%)*
- *The service received was at a lower level than required (29.8%).*¹²

Carer recognition

The Act must better recognise and support carers, to enable them to provide the best care possible and maintain their own wellbeing. It is pleasing that carers have been defined in Section 7, however, for consistency, we suggest this definition aligns or refers to the *Commonwealth Carer Recognition Act 2010*.¹³ This will help ensure consistent language across Commonwealth Legislation and associated documents, policy and programs. An example of a relevant document that uses this carer definition is the Aged Care Quality Standards Final Draft.¹⁴

An excerpt from Section 20 of the Exposure Draft states:

“An individual has a right to opportunities, and assistance, to stay connected (if the individual so chooses) with: (a) significant persons in the individual’s life and pets, including through safe visitation by family members or friends where the individual lives and visits to family members or friends.”

Including the word ‘carer’ in this section would legislate rights for older people and their carers, aligning with the recommendation from the Key Issues Paper regarding people in respite having an absolute right to visitors. Importantly, the Act must legislate the right for older people to have visitors, particularly in palliative, end-of-life, or other required situations. COVID-19 brought about many ‘lock down’ scenarios whereby older people were not able to have in-person contact with their family and carers. From the pandemic experience, we know that there are safe methods of visitation (within the bounds of public health orders) that uphold personal wishes and rights.

¹¹ Carers Australia. (2018). *Improving access to aged residential respite care*. Available from: <https://www.carersaustralia.com.au/wp-content/uploads/2020/07/final-residential-respite-care-report-2-1.pdf>

¹² Carers NSW (2023). *2022 National Carer Survey: Full report*. Available from: <http://www.carersnsw.org.au/research/survey>

¹³ Carer Recognition Act 2010. (Cth). Available from: <https://www.legislation.gov.au/C2010A00123/asmade/text>

¹⁴ <https://www.health.gov.au/sites/default/files/2023-12/the-strengthened-aged-care-quality-standards-final-draft-november-2023.pdf>

The Carers Tasmania: COVID Impact Survey 2022 found that 61.5% of respondents indicated the person they care for had experienced a lockdown whilst in permanent care in an aged care facility, and 7.7% reported that the person they care for experienced a lockdown whilst in respite at a residential aged care facility.¹⁵ Of the carers who had experienced a lockdown, 34.8% said the lockdown lasted for a week or less, 31.03% reported that it lasted for a fortnight, 13.79% a month, 13.79% longer than a month and 6.9% longer than six months.¹⁶

The Exposure Draft Consultation Paper states that carers have not been included within the Statement of Rights, explaining that carers are covered under their own legislation. To link these two pieces of legislation together in a collaborative and supportive manner, the new Act must explicitly refer to the *Commonwealth Carer Recognition Act 2010*.¹⁷

Recommendation One of the Aged Care Royal Commission states “*The new Act should define aged care as: supports, including respite for informal carers of people receiving aged care.*” Despite this, the Exposure Draft fails to include any provisions for support to carers such as respite. It is integral that specifications are included to enable carers to have a break when they need it so they can look after their own wellbeing, rest, and recover to effectively continue providing carer when respite ends.

An example of a Commonwealth Act that includes respite provisions for carers is the *Disability Services and Inclusion Act 2023* (Cth), which provides:

“8 Definitions

Respite care supports or services means supports or services to provide short term care for a person with disability, as an alternative care arrangement, for the purpose of giving relief or assistance to:

- (a) the person with disability; or*
- (b) the family members or carers of the person with disability; and*

13 Arrangements and grants

(1) The Minister may, on behalf of the Commonwealth, make, vary, or administer an arrangement for the making of payments by the Commonwealth to a person, or make, vary or administer a grant of financial assistance to a person, in relation to one or more of the following activities (the eligible activities):

- (e) the provision of carer supports or services.”¹⁸*

We recommend that Section 392 of the Exposure Draft be amended to legislate that grants have capacity to provide appropriate and timely support to carers.

Sections 43 to 45 do not explicitly describe the potential to include carers within the new aged care Integrated Assessment Tool (IAT) assessment process, despite the *IAT Live Trial*

¹⁵ Carers Tasmania. (2022). *COVID Impact Survey Report 2022*. Available from: <https://carerstas.org/wp-content/uploads/2023/08/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

¹⁶ Ibid.

¹⁷ Carer Recognition Act 2010. (Cth). Available from: <https://www.legislation.gov.au/C2010A00123/asmade/text>

¹⁸ Disability Services and Inclusion Act 2023. (Cth). Available from: <https://www.legislation.gov.au/C2023A00107/latest/text>

*Final Report*¹⁹ describing a component of the assessment pertaining to carers. To ensure that item 11 in the Exposure Draft, under the Aged Care Rights - Statement of Rights is upheld, the Act must legislate for aged care assessments to acknowledge, include, and respect the needs of carers, ensuring that their concerns are considered in support planning and that they can within their own right be referred to appropriate support. This could be included under section 44 – Undertaking aged care needs assessments.

Item 11 from the Statement of rights is as follows:

*(11) An individual has a right to have the role of persons who are significant to the individual, including carers, be acknowledged and respected.*²⁰

In addition, the Aged Care Royal Commission Recommendation 28 specifies that aged care assessments must “include an assessment of any informal carer’s needs.” We recommend that this be legislated.²¹

A stronger disability focus

Although this legislation is focused on improving the supports available for older people, it is important to acknowledge that a large proportion (49.6%), or one in two Australians over 65 years, have disability.²² Despite this, the Exposure Draft appears to take a focus on ‘ill health’ as opposed to disability.

For example, the Exposure Draft states that the objects of the Bill are to:

“in conjunction with other laws, give effect to Australia’s obligations under the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of Persons with Disabilities (CRPD).”

We urge a stronger focus on disability within the Act, including a commitment to provide adequate support to older people who have disability. Specifically addressing this need within the legislation will help ensure that older people can receive high quality care even if they have a disability that requires more complex care. Australia’s formal care system must better cater for the specific needs of people based on their actual needs as opposed to their age.

We recommend that disability (for those who also meet age requirements) is specifically included within the Act as an eligible reason to access aged care supports.

Clear eligibility guidelines for early access to aged care services

Whilst it is broadly understood that access to aged care services is for assessed for people over 65 years of age, for those over 50 if they are Aboriginal or Torres Strait Islander, or those who are at risk of or are experiencing homelessness and are aged at least 50, the legislation does not provide clear guidelines on access for those in other circumstances that may result in a person needing access to aged care support earlier. There are people who

¹⁹ Australian Government Department of Health and Aged Care. (2023). *Integrated Assessment Tool (IAT) Live Trial Final Report*. Available from: <https://www.health.gov.au/resources/publications/iat-live-trial-final-report-2023?language=en>

²⁰ Aged Care Bill Exposure Draft 2023 (Cth). Available from: <https://www.health.gov.au/sites/default/files/2023-12/exposure-draft-aged-care-bill-2023.pdf>

²¹ Commonwealth of Australia. (2021). *Royal Commission into Aged Care Quality and Safety. Final Report Volume 1*. <https://www.royalcommission.gov.au/system/files/2021-03/final-report-recommendations.pdf>

²² Australian Bureau of Statistics. (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. ABS. Available from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>.

do not fit the age requirements but need specific support and are also not eligible for other supports such as the NDIS. We strongly encourage clearer eligibility guidelines be provided with this regard. Regardless of age, the Australian Government must ensure that there are clear, accessible pathways for people who need support to access it.

Advocacy, information, and navigation services

The Act must include provisions to ensure that professional independent advocacy, information, and system navigation services, for older people and their carers remain functional and funded to ensure accessibility. Legislation must help safeguard the continuation of these important supports. As such, the Act must specify the continuation of funding for the National Aged Care Advocacy Program, along with sufficient funding for information and navigation supports. These services are particularly valuable in communities where there are lower literacy and digital literacy rates, and in marginalised or diverse communities. There is a risk that if the continuation of these valuable supports is not legislated, that they will diminish. It is also important to highlight that not everyone who is a carer has the skills to comprehend and understand paperwork, processes, and legislation, therefore these supports must extend to assist the carers of people accessing aged care services.

As highlighted in the Key Issues Paper, the current *Aged Care Act 1997*(Cth),²³ and the *NDIS Act 2013* (Cth)²⁴ both include provisions for the National Aged Care Advocacy Program. However, the Exposure Draft does not include such provisions for independent advocacy. The Exposure Draft Statement of Rights describes the right for advocacy:

Aged Care Rights – Statement of Rights:

*(10) An individual has a right to be supported by an advocate or a person of the individual's choice, including when exercising the individual's rights in this section, voicing the individual's opinions, making decisions that affect the individual's life and making complaints.*²⁵

The Act must go one step further and ensure that advocacy services remain available and accessible.

The Act must specify that people using aged care services are to be supported to understand their rights, how to make a complaint, and what independent advocacy support is available for them. Covering these points in writing only is inadequate.

The 2022 National Carer Survey found that a large proportion (60.5%) of carer respondents had been provided with all the information they needed when engaging with aged care services. However, 19.8% of respondents had not.²⁶ The provision of information and navigation support is critical, especially within jurisdictions such as Tasmania where there are challenges with literacy, digital literacy, and connection.

Recommendation 29 of the Aged Care Royal Commission (the Royal Commission) refers to ensuring that there are appropriate care finders available who will assist older people and their carers to navigate the aged care system and access sufficient support. Although this

²³ Aged Care Act 1997 (Cth). Available from: <https://www.legislation.gov.au/C2004A05206/latest/text>

²⁴ National Disability Insurance Scheme Act 2013 (Cth). Available from: <https://www.legislation.gov.au/C2013A00020/latest/text>

²⁵ Aged Care Bill Exposure Draft 2023 (Cth). Available from: <https://www.health.gov.au/sites/default/files/2023-12/exposure-draft-aged-care-bill-2023.pdf>

²⁶ Carers NSW (2023). 2022 National Carer Survey: Full report. Available online at: <http://www.carersnsw.org.au/research/survey>

program has commenced, the eligibility is not as extensive as the recommendations in the Royal Commission, rather, the support is prioritised for those in deemed to be in extreme need, and in a lot of cases if there is a family or friend carer, they are deemed ineligible.

We know that many carers supporting an older person are older people themselves. In addition, many carers have their own disability or health concerns. Many are also juggling other responsibilities such as employment, study, or raising a family. We must also not forget that some parts of Australia are impacted more than others by low literacy rates and poor digital inclusion. We recommend that the function and funding of care finders be legislated within the new Act. In addition, it should be expanded to support more people and that the eligibility requirements of access are more inclusive, aligning with the Royal Commission recommendations.²⁷

The diverse needs of older Australians

Pleasingly, the Exposure Draft includes specific items that use the terminology of culturally safe and appropriate, trauma aware, and healing-informed.

This Act will provide the scaffolding for aged care supports, therefore, it must legislate to ensure that services are able to deliver these supports. It could include regulations on providers to ensure that their staff are specifically trained to meet diverse needs. This would align with the following items from Recommendation 30 of the Aged Care Royal Commission:

As a condition of approval or continued approval of providers, training on cultural safety and trauma-informed service delivery be provided for all workers engaged by providers who are involved in direct contact with people seeking or receiving services in the aged care system.

As a condition of approval or continued approval, providers verify to the satisfaction of the System Governor that the provider has proper grounds for making any representation of being able to provide specialised services for groups of people with diverse backgrounds and life experiences.

Formulate a standard dataset and data collection mechanism for collecting, monitoring, analysing and using data about the diverse backgrounds and life experiences of older people seeking or receiving aged care, including, as considered appropriate, people whose circumstances are not currently included in the 'special needs' provision, such as those living with mental illness, dementia or disability.²⁸

Restrictive practices

Whilst the *Aged Care and Other Legislation Amendment (Royal Commission Response) Act 2022*²⁹ introduced stronger controls over the use of restrictive practices for older people, the process is not consistent or as stringent as when used within the disability sector, leaving room for inappropriate use of restrictive practices under 'urgent or emergency' situations. More clarification and protections are required in the Exposure Draft, especially to protect older people from restrictive practices such as chemical restraint.

²⁷ Commonwealth of Australia. (2021). *Royal Commission into Aged Care Quality and Safety. Final Report Volume 1*. <https://www.royalcommission.gov.au/system/files/2021-03/final-report-recommendations.pdf>

²⁸ Ibid.

²⁹ Aged Care and Other Legislation Amendment Act.(2022). <https://www.legislation.gov.au/C2022A00034/latest/text>

The Aged Care Act: Exposure Draft – Consultation Paper No.2 describes that “providers in certain registration categories must comply with strict requirements prescribed by the Rules in relation to restrictive practices,”³⁰ however, these rules are not as stringent as those protecting people with disability from the use of restrictive practices.

Although the Exposure Draft explains that representatives and supporters are not automatically authorised to consent to the use of restrictive practices, they should be involved in discussion about the need for such practices to be used under certain circumstances. The Exposure Draft also does not legislate the need for a Behaviour Support Plan, which is required under other Commonwealth funded programs such as the NDIS. The requirement for Behaviour Support Plans must be explicitly included within the legislation. The legislation must outline that these plans must be completed by suitably qualified professionals, and they must clearly state the type of restrictive practice that has been authorised for use in only in cases where the older person poses a serious risk of harm to themselves, or others and no other more appropriate intervention has worked.

Rules around the use of restrictive practices should not differ depending on the age of a person. All people have the right to be safe from practices, unless they are posing an immediate risk of harm to themselves or others.

Supporters and representatives

Section 38 (requests for aged care assessments) must legislate for older people and their carers to be informed of the process to appoint and apply as a representative or supporter in the initial stages of investigating aged care services. It is important that accessible and clear information is available, so that older people and their carers understand what their rights are within the context of supporters and representatives. It is reasonable to foresee that there will be some level of confusion about supporters and representatives, and the difference between those functions and guardianship and power of attorney.

The Exposure Draft specifies that:

(1) A person must not make a decision under, or for the purposes of, this Act on behalf of an individual unless the person is appointed as a representative of the individual under section 376.

(2) Subsection (1) applies even if the person:

(a) has guardianship of the individual under a law of the Commonwealth, a State or a Territory; or

(b) is appointed by a court, tribunal, board or panel (however described) under a law of the Commonwealth, a State or a Territory, and has power to make decisions for the individual; or

(c) holds an enduring power of attorney granted by the individual; or

(d) is a nominee of the individual (within the meaning of the National Disability Insurance Scheme Act 2013 or the Social Security (Administration) Act 1999); or

(e) is a person of a kind prescribed by the rules.”

³⁰ Australian Government Department of Health and Aged Care. (2023). *Aged Care Bill Exposure Draft, Consultation Paper No.2, 2023*. Available from: <https://www.health.gov.au/sites/default/files/2024-02/a-new-aged-care-act-exposure-draft-consultation-paper-no-2.pdf>

As drafted, this means that even if a carer has been legally appointed with guardianship and/or power of attorney, they still need to be assessed to be the representative or supporter for aged care purposes. This is likely to be confusing to carers and older people, who will have assumed that guardianship or power of attorney is sufficient to provide decision making authority. As such, advocacy, information, and navigation support must be legislated within the Act.

The proposed changes around supported decision-making mean that carers will have to 'apply' for the authority to assist with decisions, even if they have legal authority already. There will be a specific supported decision-making process they will need to follow, and it is important that adequate, accessible information is provided on what this entails.

There must also be consideration of urgent or emergency situations where a person is requiring urgent or emergency aged care support but may have not had an assessment prior to this event.

It is concerning that the Exposure Draft now specifies that a person may have more than one of either representatives or supports, however, they can only have one or the other, not both a supporter and a representative. This idea differs from other government supports such as the NDIS whereby a person may have both a correspondence nominee and a plan nominee, acknowledging the different roles that occur, particularly within families in supporting someone.

To provide an example within the context of age care, a wife who lives with her husband might be his primary carer, assisting him with practical and emotional support daily. They may have a daughter who lives separately who assists them with information and understanding paperwork and financial responsibilities. The wife might have guardianship and the daughter might have power of attorney. If this is what works best for an older person, then this is what should be allowed, given that the System Governor is satisfied they both meet eligibility requirements.

Given that the Exposure Draft imposes increased requirements for supported decision-making, representatives and supporters must also be provided with additional information and resources on this concept and their responsibilities. We also recommend that older people are able to have both a supporter and representative.

Whistleblower protections

It is positive that additional whistleblower protections have been specified within the Exposure Draft. It is vitally important that there are easy avenues by which people with genuine worries about the safety of older people can raise their concerns to help reduce elder abuse and neglect without fear of reprisal. Every concern about the safety of older Australians should be taken seriously.

Over the years, carers have often reported they are afraid to complain about the quality of services or particular employees due to fear of reprisal. Some have claimed that they were treated poorly or experienced a reduction in services. Others have reported that carers have not been listened to, or because they were not a legal guardian, they weren't taken seriously. The introduction of whistleblower protections also may encourage others such as staff members and members of the public to speak up. We recommend that there is clear communication about this to older people, their carers, to employees and the wider community.

Undrafted sections of the Bill

The Draft Bill has several undrafted sections including:

- Section 130 – Chapter 4 - Fees, payments and subsidies:
 - Part 1 - Introduction
 - Part 2 - Means testing
 - Part 3 - Subsidies
 - Part 4 - Payments and fee arrangements
- Section 64:
 - Part 4 – Prioritisation
 - Part 5 – Place allocation
- Section 285: Part 11 – Critical failures powers
- Section 362: Part 2 – Review of decisions

Once drafted, these sections must be publicly shared to ensure transparency and enable opportunity for public consultation and feedback.

Recommendations

To summarise, our recommendations are as follows:

- No further delay in implementation of the Act.
- A legislative review should occur at the three-year mark.
- To uphold choice, control and human rights, there must be better support for providers.
- Review the definitions with an aim to be more inclusive and use clearer language.
- Amend the complaints process and include it within the Act.
- Timely access to support must actually occur.
- Improve carer recognition and refer specifically to the *Carer Recognition Act*.
- Amend Section 392 of the Exposure Draft to legislate that grants must provide appropriate and timely support to carers.
- Ensure there is adequate support for older people with disability.
- Include clear guidelines for early access to aged care support.
- Legislate the continuation of funding for advocacy, navigation and information services.
- Regulate specific training to ensure all providers can meet the diverse needs of older Australians rather than only high-quality providers.
- Legislate improved protective factors for older people to reduce the use of restrictive practices.
- Streamline the process for supporters and representatives and ensure that adequate information and support is available.
- Allow older people to have both supporters and representatives.
- Deliver appropriate communication about whistleblower protections.
- Ensure there is transparency and consultation when the undrafted sections of the Bill are available.