

Response to the Australian Government Department of Health and Ageing – Consultation 2 to Develop the New Regulatory Model for Aged Care

23 June 2023

Introduction

Carers Australia welcomes the opportunity to respond to stage 3 of the consultation process to develop the new regulatory model for aged care by the Australian Government Department of Health and Ageing (the Department), specifically to provide comment on the second consultation paper with details of the proposed model (the Consultation Paper)¹. We applaud the actions to increase protections for older people and empower them to exercise their rights in the context of a reformed and improved aged care system, and firmly believe these rights must be outlined in a Statement of Rights to be included in the new Aged Care Act.

We appreciate the consultations over recent years involving providers and professionals, consumers of aged care services and their families, carers and organisations representing the people who are or will be accessing aged care services and those who care for them. We also acknowledge and agree that the new model will place older people at the front and centre.

Carers Australia are conscious that terminology can have negative connotations for many people and acknowledge that not everyone's experience is properly captured by terms. We are supportive of efforts to influence respectful and inclusive language about older people and combat ageism; however, inclusivity must also extend to language related to carers and caring. As such we choose to respectfully use terms in this response, recognising the diversity of carers, care relationships and those receiving care.

It is our role as Carers Australia to provide information from a carer² lens, and that is our necessary focus, where we are encouraged to see the Consultation Paper identifying that a facilitator to supporting quality care is the provision of 'information for older people, their families and carers (p.17). However we remain concerned about recognition of the need for the voice of carers of older people accessing aged care services, as well as older carers (distinct from 'consumers', family or representatives), each having different needs that are not necessarily met by organisations unaware of the complexities of caring - and how this interfaces with the aged care system.

The latest data from the Survey of Disability, Ageing and Carers (SDAC), indicates that 772,000 people over the age of 65 (including 156,400 people over the age of 85) were being cared for by a family member or friend in 2018.³ Almost two-thirds (64.9%) of primary carers providing care to a parent were aged between 45 and 64 years, with 36% providing this care for a parent for between 10-24 years.

¹ Australian Government, Department of Health and Ageing, April 2023, 'A new model for regulating aged care: Consultation Paper 2 – details of the new model' [[accessed online](#)]

² Carers Australia uses the term 'carer' as defined by the *Commonwealth Carer Recognition Act 2010* (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

³ Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, (2018)[[accessed online](#)]

This is distinct from older carers who are aged over 65 years themselves, which was 34% of all primary carers in 2018. While it is likely many of these older carers are also consumers of aged care services, the caring relationship(s) they have can be complex which has implications for their aged care, health and broader support needs. In 2018, a quarter of all carers (647,200) were over the age of 65, including 228,800 primary carers⁴. In many cases an older carer is caring for a person also accessing aged care services, noting 54.8% of primary carers providing care to a spouse or partner in 2018 were aged 65 years and over. However, older carers may also be caring for an adult child with disability, mental illness or life-limiting condition, or be a 'grandparent carer' to a younger child with disability, mental illness or life-limiting condition.

The accessibility, adequacy, quality and safety of aged care delivery is of central importance to these carers. They are concerned with the wellbeing of the people they care for and want them to have the range and quality of formal aged care services they need, want and deserve, and most often fill the gaps in paid aged care or other service provision. In the absence of accessible, adequate, high quality and safe aged care carers may experience distress and in some cases guilt that they were 'not observant enough' or 'present enough' to prevent the situation arising. They may feel they must try to remedy the situation themselves or take on a more intensive caring role rather than rely on formal paid care or substitute care.

Carers Australia has had a necessary focus on aged care reform processes following the Royal Commission into Aged Care Quality and Safety (Royal Commission), noting our specific work in advocating for carers during development of the regulatory model including:

- The Stage 1 early concept paper through the National Aged Care Advisory Council
- As a member of several formal committees convened by the Department
- Engagement on the proposed approach to consultation
- Feedback on Stage 2 Consultation Paper No.1 – A new model for regulating Aged Care
- Service characteristics and risk assessment co-design workshop, and
- Stage 3 workshops, including communicating the workshops for carers participation.

Our response is also informed by our members - the state and territory peak advocacy organisation for carers, which collectively form the National Carer Network, and previous and ongoing representation on development of the new Aged Care Act and broader aged care reform pieces that intersect with the regulatory model, including through our submissions on development of the [new Program for In-Home Aged Care, Strengthening Aged Care Provider Governance](#), the [Residential Aged Care Accommodation Framework](#), and the [Serious Incident Response Scheme in Commonwealth funded In-Home Aged Care](#).

Importantly, carers often play an active role in holding providers and paid care and support workers to account for poor quality care and can be key participants in changing the culture of aged care services. As such, we bring to the Department's attention that while the negative consequences of unavailable and/or poor-quality care on the older person receiving the care is first and foremost, the additional impact on a person's carer can be profound and can impact on the 'informal' subsequent care and support that is able to be maintained without additional paid services or entry into residential care.

⁴ Ibid.

Response to the Consultation Paper

Clear identification of carers in the regulations

There are very few direct references to carers, or indeed to families, in the Consultation Paper.

The main reference is to older people and their ‘representatives’, however there is no definition of ‘representatives’ in the glossary of the Consultation Paper. Further ambiguity is provided by using the term ‘families and carers (representatives)’ in relation to complaints and feedback mechanisms specifically (p.11).

We strongly believe use of the term ‘representatives’ in this way can cause confusion and be interpreted in many ways, including a term specific only to those with formal legal status, such as guardianships or powers of attorney.

Further evidence for the need to use clear and consistent carer-inclusive language for the new regulatory model is provided by the Aged Care Quality and Safety Commission (ACQSC), where in their guidance for providers on the Code of Conduct for Aged Care, there are requirements to engage with ‘representatives, family members and carers’ throughout the document, although this document also unfortunately does not include a definition for ‘representative’ in the glossary⁵. However, the ACQSC online glossary does have clear definitions:

“Carer – A person who provides personal care, support and help to a consumer. This does not include members of the organisation’s workforce, or people the organisation contracts or pays to provide those services, or people who provide the services as a volunteer. This definition is in line with the [Carer Recognition Act 2010](#).”

“Representative – Defined in the Section 5 of the [Records Principles 2014](#) as:

- a. a person nominated by the care recipient as a person to be told about matters affecting the care recipient; or*
- b. a person:
 - i. who nominates himself or herself as a person to be told about matters affecting a care recipient; and*
 - ii. who the relevant approved provider is satisfied has a connection with the care recipient, and is concerned for the safety, health and wellbeing of the care recipient.**

(2) Without limiting subparagraph (1)(b)(ii), a person has a connection with a care recipient if:

- a. the person is a partner, close relation or other relative of the care recipient; or*
- b. the person holds an enduring power of attorney given by the care recipient; or*
- c. the person has been appointed by a State or Territory guardianship board (however described) to deal with the care recipient’s affairs; or*
- d. the person represents the care recipient in dealings with the approved provider.”*

⁵ Aged Care Quality and Safety Commission, Code of Conduct for Aged Care – information for providers [[accessed online](#)]

Carer rights are established in existing legislation where the *Carers Recognition Act (2010)* includes the right of carers to be treated with dignity and respect and to be regarded as partners in care.⁶ Their right to support through aged care services was reinforced by the Royal Commission, and indeed in its first recommendation the Commission included such support in the definition of aged care under the new Act.⁷ This includes the right to be supported in their caring role⁸ and that the Aged Care Quality and Safety Authority should actively engage with older people and their families and carers to ensure that their views are incorporated in the Authority's compliance and decision-making, and are kept informed of the outcome of regulatory activities.⁹

These rights are not restricted to formal 'representatives' and it is important that the language used in regulations, and indeed across government departments and authorities and service providers, is very explicit to avoid unintended interpretations.

We also note further issues with use of the term carer in aged care policy which has potential to impact on interpretation of the language used in the regulatory model:

- The Government's 'Partnerships in care' program for family and friends of those in residential aged care, to help continue to provide care and companionship to the older person, noting no use of the word 'carer' and language used within the *Carer Recognition Act (2010)* of carers being 'partners in care'. While we strongly support the any activities that enable social engagement and the continuity of close relationships, the language is not carer-inclusive, noting the programs [Fact sheet](#) states "A partner in care (also referred to as a partner) is a person identified by the aged care resident, or their representative, who they have a close and continuing relationship with, such as a family member or close friend. A partner regularly visits and provides care and companionship to the aged care resident."
- The proposed in-home support model of aged care includes "explicitly funding care partners to monitor older Australians' clinical needs and support them when they need help." As stated in [our submission](#) to the recent discussion paper on this model, while the underlying principle is a welcome development, using this language will add another layer of complexity to carer recognition and navigating the aged care system more broadly for all Australians.

We strongly recommend that the language used throughout the regulations should refer to carers and families (or just to carers where carer-specific assessment and support services are concerned), and the term 'representatives' or any other terms are clearly defined and provided in context.

Caring may involve ongoing and high intensity care and support of many aspects of one's lives, can involve activities that paid 'formal' roles might offer if they were available, accessible and affordable, and is done most often without adequate access to respite. A carer's role is distinctively different from generalised familial support and the information needs are different, especially as it relates to safeguarding participants and decision-making. And as noted by the Royal Commission, informal caring also does not end if the older person enters residential aged care¹⁰.

⁶ Parliament of Australia, *Carers Recognition Act (2010)* [\[accessed online\]](#)

⁷ Royal Commission into Aged Care Quality and Safety, 2021, Final Report, List of Recommendations, Recommendation 1-2 (b), [\[accessed online\]](#)

⁸ Ibid., Recommendation 3 (iii and vii)

⁹ Ibid. Recommendation 10:2

¹⁰ The Royal Commission into Aged Care Quality and Safety, 2029, 'Carers of Older Australians Background Paper 6' [\[accessed online\]](#)

We also highlight that there is no clear definition of family, and this is inconsistent with increasing diversity and recognising a person's family of choice who may not be biological relatives and should also not be referred to as 'friends'. Similarly, an older persons carer may be a close friend, increasingly the case due to people having fewer children over time, older ethnically and culturally diverse Australians having fewer relatives also in Australia and the rise in single person households, particularly for women.

To this end we note announcement of an [Inquiry into the recognition of unpaid carers](#) by the House of Representatives Standing Committee on Social Policy and Legal Affairs on 14 June 2023. As highlighted in our [media release](#), Carers Australia are pleased to see that the new Inquiry's Terms of Reference are broader than simply a definition of 'who is a carer', and includes developments in the policy landscape at a Commonwealth level since introduction of the *Carer Recognition Act* in 2010, and the Government's broad agenda in relation to the care and support economy.

Supporting Quality of Care – Information for older people, their families and carers

Carers Australia agree that the introduction of Star-Ratings will play an important role in assisting older people and their carers and families to choose residential aged care facilities and to keep track of the performance of their facility once they have entered into residential care. Indeed, we would consider it of great importance that Star Ratings are also introduced to evaluate the performance of providers in the new In-Home Support program.

We will watch with great interest the impact of more publicly available and easily accessible information about provider performance, and if this includes a reduction in the number of people who access residential respite for the purposes of a "try before you buy" experience (i.e., to evaluate the residential facility as a suitable choice for permanent residence). According to the 2021-22 Report on the Operation of the Aged Care Act¹¹, 70,993 people received residential respite care, of whom 41,696 (approximately 58.7%) were later admitted to permanent care. We have had representation that it is likely a high proportion of these were accessing respite for "try before you buy" purposes as opposed to genuine respite. While we understand why respite opportunities may be used in this way, it can block opportunities for genuine respite needs and we continue to hear from carers and our member associations that residential respite can be difficult to access.

However, we note with concern that the Star Ratings system is unlikely to capture the experience of respite care given the short stay of respite residents. The general performance of the facility will certainly be an indication of the quality of care provided to long-term residents who have settled in, but not necessarily for those who are moving through and who may require more intensive assistance to adjust to the environment and establish their care needs with staff, especially if the person accessing respite care has dementia.

We recommend that a mechanism for facility-based evaluation of residential respite which incorporates the experiences of respite residents and their carers is developed, and a reporting requirement with information also publicly available.

We also recommend that such mechanisms should extend to community aged care respite facilities.

¹¹ Department of Health and Aged Care, 2021-22 Report on the Operation of the Aged Care Act 1997, [\[accessed online\]](#)

Provider Registration

We broadly agree with the six registration categories based on common characteristics and associated service risks which, along with the streamlining of the current 300 provider responsibilities, will remove unnecessary administrative disincentives and encourage innovation.

While we are pleased to see a separate category for Home and Community Respite (Category 5), we note that there are some marked differences between providing paid care in the home for respite purposes and providing group care in a dedicated facility, such as a respite cottage or a day care program.

In particular, activities under Social Supports (Category 3) are often combined with both day care and day/night respite for short periods. Social activities and peer support are made available both to the person receiving respite care and to their carers.

It is not clear if providers of respite whose services involve both replacement care and social activities, and in some cases carer educational activities, would need to be registered under both Category 3 and Category 5.

We are also pleased that sole traders and partnerships will be able to register to deliver in-home services and that such registration will provide access to an aged care subsidy, as outlined in [our submission on indirect employment](#). The capacity of aged care consumers to exercise choice and control is manifested in its most obvious form through self-management of home care packages. Among other things, self-management empowers consumers and carers to directly choose who they want to provide services to them and can be more conducive to achieving continuity of care from the same paid aged care workers than reliance on provider staffing arrangements.

Continuity of paid aged care workers can be especially important to respond to the diversity of older people and their needs. For example, people with dementia who may find it difficult to adjust to unfamiliar care workers. The ability to directly employ support staff can also make it easier to find paid aged care workers for culturally and ethnically diverse older people who need someone who speaks their language and shares or understands their cultural requirements. It also supports older people who identify as LGBTIQ+ so they can be more confident they will be treated with greater understanding, dignity and respect. Additionally, it may be important for people to receive certain or all paid care services by someone of the same faith or of a particular gender, especially for personal care. Flexible models of direct employment can also be useful for carers seeking to balance paid care work with their unpaid care responsibilities.

An additional issue is whether registration for sole traders will have any impact on the necessity for a consumer who is self-managing their package to also be connected with a home care provider for the purposes of care and package management.

We have had a number of complaints about this requirement from both consumers and their carers who may be assisting them to directly employ staff. Consumers are told their package belongs to them, not to a provider. They, or their carers, do all the service selection, organisation and administrative work. However, under current regulations, a proportion of their package must be paid to a provider for doing what consumers and their carers perceive as little more than paying bills and tracking expenditure. Provider engagement in managing packages of support does not apply to the National Disability Insurance Scheme (NDIS), and while we acknowledge that self-managing NDIS recipients and their carers can experience a high administrative burden, we highlight the opportunity in the new regulatory model for administrative

processes to be streamlined without reducing quality and accountability, while maintaining the priority of people having choice and are able to use their funds to extract the most value from their perspective.

The Code of Conduct

With respect to the Code of Conduct, the observance of which will be a core condition for all providers under the new registration arrangements, we note that Table 3 on page 42 of the Consultation Paper highlights acting in a way that treats people with dignity and respect and values their diversity, but only with respect to consumers.

This is again out of alignment with the ACQSC inclusion of carers, families and representatives in the guidance for providers as highlighted previously¹² and does not reflect recommendations within the Royal Commission, including that *“the relationships that older people have with significant people in their lives should be acknowledged, respected and fostered.”*¹³

It is also not consistent with the *Carers Recognition Act (2010)* and Statement for Australia’s Carers which includes the following principles:¹⁴

- “5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.*
- 6. The relationship between carers and the persons for whom they care should be recognised and respected.*
- 7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*
- 8. Carers should be treated with dignity and respect.”*

Carers Australia want carer and family rights to also be treated with dignity and respect and this explicitly guaranteed in the Code.

We draw to the Department’s attention that the *Carer Recognition Act (2010)* also outlines different parties’ responsibilities in respect of the Statement of Australia’s Carers and sets up reporting and consultation arrangements for certain Australian Public Service (APS) agencies, public service care agencies and associated providers, and that nothing in any other legislation should in any way limit or narrow the scope of the Carer focused Act¹⁵.

We would consider the Department and ACQSC to be public service care agencies¹⁶ which have the following obligations per the Act:

- Each public service care agency is to take all practicable measures to ensure that it, and all its employees and agents, take action to reflect the principles of the Statement for Australia’s Carers in developing, implementing, providing or evaluating care supports (Part 3 s8(1)), and

¹² Op.cit. (5) ACQSC

¹³ Op.cit. Recommendation 3 (vi)

¹⁴ Op. cit. (6) *Carer Recognition Act 2010*

¹⁵ Australian Government, 2016, ‘Carer Recognition Act 2010 Guidelines: A guide for Australian Public Service Agencies for the implementation of the Carer Recognition Act 2010’ [[accessed online](#)].

¹⁶ Ibid. p.5 where public service care agencies are defined under the Act as those agencies that are responsible for the development, implementation, provision or evaluation of care supports, and ‘care supports’ are defined as “any policies, programmes or services that are directed to carers or the persons for whom they care. This refers to any policy, programme or service that targets carers as a priority group within Australia, or targets the people for whom they care.”

- Each public service care agency is to consult carers, or bodies that represent carers when developing or evaluating care supports (Part 3 s8(2)).

Carers Australia recommend the obligations of the *Carer Recognition Act (2010)* are provided to aged care providers registered under the new arrangements.

This is noting that associated providers¹⁷ also have an obligation to increase staff awareness of what a carer is, as defined under the Act, and 'reflect and have due regard' for the in the Statement for Australia's Carers.

We are also aware that it is intended the new Aged Care Act will have a Statement of Rights, and registered providers will be expected to provide aged care services in a manner consistent with these rights.

We recommend that the Statement of Rights under the new Aged Care Act be embedded in contracts between aged care providers and consumers.

Further, aged care consumers should be made aware of their rights and remedies under Australian Consumer Law if their complaints cannot be resolved through the aged care system.

¹⁷ Ibid. p.7 Associated providers are defined under the *Carer Recognition Act (2010)* as "people or bodies contracted or funded by public service care agencies to develop, implement, provide or evaluate care supports, that is policies, programmes and services that are directed to carers and the people they care for, and their immediate subcontractors."

About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represents the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

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