

Response to the Australian Government Department of Health and Aged Care – Consultation on the Exposure to Draft of the New Aged Care Act

February 2024

Introduction

Carers Australia welcomes the opportunity to respond to the Exposure Draft of the New Aged Care Act.

While we have an interest in all aspects of the Act as it impacts on older people, we have focused our submission on those parts of the Act which most directly deal with carers' engagement with aged care and their rights to recognition and support. The sections of the Act relating to representatives and supporters are also of central interest to carers, whether or not they fulfil these roles.

Our views in relation to other areas of the Act are reflected in the Joint Response to the Aged Care Act Exposure Draft by the National Organisations Working with Older People and Carers.

The case for a more carer inclusive Aged Care Act

The contribution of unpaid carers of older people is critical to the sustainability of the aged care system. In 2020 Deloitte Access Economics calculated that family and friend carers provided nearly 2.2 billion hours of care, comprised of 1.7 billion hours from primary carers and 491 million from non-primary carers. Thirty five percent of these carers were caring for someone over the age of 65 and a quarter of carers were themselves over the age of 65. The replacement cost of this care (replacing unpaid care with paid care) was valued at \$77.9 billion in 2020. The demand for unpaid care and the scale of its replacement cost will grow substantially as the baby boomer generation hits the aged care system and as life expectancy increases.

However, providing this valuable support to the people they care for and to the aged care system can come at a substantial cost to carers' own welfare. Survey after survey, going back for over two decades, attest to the poor physical and mental health of carers, their susceptibility to burn-out, and their difficulty in accessing supports for themselves.

With respect to carers of older people, the last annual Carer Wellbeing Survey¹ undertaken by the University of Canberra in partnership with Carers Australia revealed that:

- 48% said they regularly or always felt they had more responsibility than they could cope with
- 46% said they regularly or always felt they had lost control over their lives
- 30% said that they struggled to cope with the stress of caring activities

¹ Deloitte Access Economics, 2020, The Value of Informal Care [accessed online](#)

- 44 % said that their caring role had impacted negatively on their own health
- Only a third said they had accessed respite in the last 12 months and a third reported poor satisfaction with their access to respite (this was a quarter for those who were caring for someone with dementia).
- A quarter said they had low satisfaction with access to training and skills courses and 41% reported only moderate satisfaction with their capacity to access these services.

Carers need and deserve timely and tailored supports which address their own needs and enhance their capacity to provide care, both in their own interests and in the interests of those they care for.

The Royal Commission into Aged Care Quality and Safety recognised the vital role played by carers, while also acknowledging that they had been let down by the aged care system. It identified that:

*“The Australian Government should ensure that informal carers are properly supported. The current aged care system fails to do so and provides reactive, inadequate support. **Supports are often not provided until the strain on a caring relationship has already reached crisis point.**”²*

It made a number of recommendations³ to correct these failures.

With respect to the new Aged Care Act these included that:

- The new Act should define aged care as:
 - a. support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration in their social, mental and physical capacities to function independently*
 - b. supports, including respite for informal carers of people receiving aged care.*
(Recommendation 1:2d)
- That the rights established under the Act include:
[F]or people providing informal care, the right to reasonable access to supports in accordance with needs and to enable reasonable enjoyment of the right to social participation. (Recommendation 2d)
- That the Statement of Principles should include:
[I]nformal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need (Recommendation 3,b,iii)

However, there are very few references to carers in the Exposure Draft apart from:

- recognising carers’ contribution and their value to society,
- a reference to the non-binding *Carers Recognition Act*,
- the right of an individual to have their carer/s acknowledged and respected (as distinct to carers themselves having this right), and
- carers being recognised as partners in care with registered providers.

These inclusions are appreciated; however they do not amount to legal obligations to support carers and they do not refer to carer support services outside of mentions of respite services in

² Royal Commission into Aged Care Quality and Safety, 2021, Final Report: Care, Dignity and Respect, Executive Summary, p.103 [accessed online](#)

³ Royal Commission into Aged Care Quality and Safety, 2021, Recommendations, [accessed online](#)

residential aged care (although we acknowledge that more services for carers maybe included in revisions to the Act which incorporate home and community care once the design of home care is developed).

Against this background, the failure of the Exposure Draft to incorporate these key recommendations of the Royal Commission is deeply disappointing and disturbing.

In dealing with DoHAC and other departments whose policies and programs have significant impact on carers, Carers Australia has come across the view that carer support is the sole responsibility of the Department of Social Services since DSS is responsible for the Carer Gateway. However, the Carer Gateway is not funded to provide many of the targeted support services which carers need and which can be tailored to the age and condition of the people they are caring for. The Gateway can alert carers to support they may receive through, for example, aged care or the NDIS, and make referrals. But it is the obligation of the portfolio agency responsible for the funding and delivery of adequate, high quality and timely services to provide those services – whether that be in relation to health services, aged care services, disability services, education or employment services. Carers have consistently and persistently been treated as a low priority in the very systems which rely upon them to fill in the gaps of affordable levels of paid care delivery. The Gateway was never envisaged as a service which would allow other relevant portfolios to shrug off their responsibilities to carers.

If a perception that carers are the responsibility of another portfolio is part of the reason carers right to support is hardly touched upon in the Exposure Draft, it is erroneous and myopic.

Supporters and Representatives

In our submission to the Foundations of the Act⁴, Carers Australia identified concerns about potential conflicts arising between representatives appointed under the Act and guardianships under State and Territory law and which conferred similar decision-making powers in similar domains.

The Exposure Draft allows for the appointment of more than one representative, including a representative who has been appointed as a guardian or has a relevant power of attorney. However, we still have concerns about what happens when representatives fail to agree (unless the representatives are assigned different roles or primacy). We are very aware of the difficulty this creates for providers as well as for the older person and their families and carers, especially in cases where there is a need to make rapid decisions. We note that the NDIS Review has recommended that: “In the event of a conflict between an appointed guardian or attorney and a plan nominee, the NDIA should consider removing the plan nominee, for the duration of the appointment of the guardian or attorney⁵”; a plan nominee being a person appointed to act or make decisions on behalf of someone on the NDIS over the age of 18. It is one way of resolving the

⁴ Carers Australia, 2023, Response to the Department of Health and Aged Care Consultation on the New Aged Care Act: the Foundations [accessed online](#)

⁵ Independent Review into the National Disability Insurance Scheme, 2023, Final Report, p. 115 [accessed online](#)

matter, although in practice the plan nominee may be better placed to reflect the wishes of the person being represented.

In our previous submission we also raised the issue of difficulties regarding guardians and EPOAs automatically becoming representatives, because these people are often appointed as they were regarded as best able to deal with financial and legal matters. They may not have a very close current relationship with the older person. They may not have a good understanding of the aged care system. They may not understand the current condition and service requirements of the people they represent, even if they are family members. Those concerns we had with respect to the appointment of representatives in our first submission to the New Aged Care Act remain.

We are also puzzled as to why an older person may have more than one representative, but if they do have a representative, they may not have a supporter. Supporters can fulfil separate, very distinctive roles to representatives. Their role may, and usually does, involve providing direct assistance to an older person to help them navigate the aged care system and having close contacts with providers and their staff providing paid care in the home or in residential aged care. Just under a third of carers of older people who responded to the 2023 Carer Wellbeing Survey said they spent between one and four hours a week navigating government support systems and a further 8% said they often spent more than 5 hours a week.⁶ Not all carers want the responsibilities of fulfilling the role of representatives, including those who are themselves of advanced age. Since they are not substitute decision-makers, any conflicts which arise still put the final decision in the hands of representatives.

We note the inclusion under ***Duties of the Representative*** that when a representative is “doing a thing, or refraining from doing a thing, on behalf of the individual” they should take reasonable steps to consult “when appropriate, any other person who assists the individual to manage the individual’s day-to-day activities or, if there is not such person, any family members or other persons who have a close continuing relationship with the individual”. (Section 30, 3d)

We are unclear about whether this includes paid carers as well as unpaid carers. There should be a positive duty to at least consult with carers when making decisions (when the carer is not the representative) because:

- The carer is likely to have particularly close insight into the wishes and current needs of the older person.
- Decisions in relation to the older person may well have significant direct impacts on carers’ and wellbeing, including on their immediate and longer-term life prospects.

We are of the view that the Australian Capital Territory *Guardianship and Management of Property Act 1991*⁷ which specifies that a decision-maker must consult with each carer of the protected person, should be considered and adapted for inclusion in the Duties of Representatives in the new

⁶ Carers Australia in partnership with the University of Canberra, Carer Wellbeing Survey, 2023, data sheets available on request.

⁷ Australian Capital Territory (ACT), Guardianship and Management of Property Act 1991 [accessed online](#)

Aged Care Act. (“Carer” is defined as a person on whom the protected person relies for ongoing care assistance otherwise than because of a commercial arrangement.)

We also think the Act should include that, when the System Governor appoints representatives, the strength and currency of their connection with the person they are representing needs to be considered.

Against the comments made in this submission we recommend the following inclusions in the new Aged Care Bill

1. Legally recognise carers within the Act as eligible for support within the aged care system.
2. Incorporate carers’ right to access supports in accordance with their needs and to enable reasonable enjoyment of the right to social participation as recommended by the Aged Care Royal Commission.
3. Amend the Principles to reflect the recommendation of the Aged Care Royal Commission that carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need.
4. Under the requirements for aged care assessments in Section 44, it should be specified that, where an older person has a carer, the capacity and willingness of the carer to continue to provide current levels of care should be taken into account and carers should have the opportunity to participate in the co-design of the care plan and identify their need for respite and other service supports available to them within the aged care system.
5. Amend Section 392 to ensure grant purposes specifically includes grants to provide timely, equitable support for older people and their carers.
6. Identify the processes which can avoid a stalemate in decisions and actions where representatives disagree in order to avoid unacceptable and often deleterious delays in decision-making which impact on the older person, their carers and service providers.
7. Allow older people to have both Supporters and Representatives.
8. Under Duties of Representatives, include a duty on representatives to consult with carers when they take action or refrain from taking action on behalf of the older person.

Carers Australia appreciates the opportunity to provide feedback on the Exposure Draft of the New Aged Care Act. Our submission highlights critical areas that require attention to ensure the well-being of older Australians and their carers.

As we move toward a reformed aged care system, Carers Australia remains committed to advocating for policies that empower carers, enhance service delivery, and foster a compassionate and equitable environment for all stakeholders.

Thank you for considering our input, and we look forward to continued collaboration in shaping a future where older Australians receive the care and respect they deserve.

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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