



**Submission to the
Senate Community Affairs Committee
on the Aged Care Bill 2024**

September 2024

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

About Carers Australia

Carers Australia is the national peak body representing the diversity of the three million¹ Australians who provide unpaid care and support to family members and friends living with a disability, chronic condition, mental ill health, addiction issue, 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, 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 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.

Our carers are diverse and include those who:

- have their own care needs
- live with a disability
- are in multiple care relationships
- have employment and/or education commitments
- are 24 years and younger (young carers)
- are 65 years and over
- identify as Aboriginal and/or Torres Strait Islander
- are from culturally and linguistically diverse backgrounds (CALD)
- identify as Lesbian, Gay, Bisexual, Trans and gender diverse, Intersex, Queer, Questioning and Asexual (LGBTIQ+)
- live in regional, rural and remote Australia, and
- are former carers (no longer in a caring role)

Carers Australia endorses the [United Nations Convention on the Rights of Persons with Disabilities](#)² (UNCRPD), and we recognise that families and carers play an important role in supporting the rights of people living with a disability in line with the CRPD, where they have been nominated to do so. Carers Australia also endorses the [United Nations Universal Declaration of Human Rights](#)³ (UDHR) and how this relates to carers,

¹ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

² United Nations Convention on the Rights of Persons with Disabilities

³ United Nations Universal Declaration of Human Rights

including the right to rest and leisure and to participate in the cultural life of community (Articles 24 and 27 UDHR). Carers Australia also recognises the [Carer Recognition Act 2010 \(Cth\)](#)⁴.

Acknowledgment of country

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.



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⁴ Carer Recognition Act 2010 (Cth)

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Introduction

Carers Australia welcomes the opportunity to have input to the Committee's deliberation on the *Aged Care Bill 2024 [Provisions]* (Bill).

Along with other peak bodies with a focus on aged care, we welcome the introduction of this Bill to Parliament after a very long delay since the [Royal Commission into Aged Care Quality and Safety](#)⁵ (the Commission) published its recommendations.

Carers Australia represents Australia's three million carers, 40% of whom are primary carers – those who provide the most substantial amount of care.⁶ About a third of care recipients are over the age of 65⁷ and 60% of those providing care to a spouse or partner are themselves aged 65 years and over.⁸

Carers of older people rely heavily on the aged care system to provide adequate and timely replacement care, but also to access much needed respite, without which they are likely to experience a decline in their own mental and physical health and may not be able to continue caring at home.

Respite was a key issue identified in 55 [consultations](#)⁹ that Carers Australia recently conducted with 486 carers from across the country (this consultation was to assist and inform the Department of Social Services on the development of the National Carers Strategy), especially when caring for someone 65 years and over.

Carers Australia, in partnership with the University of Canberra, undertakes an annual National Carer Wellbeing Survey. The results of the 2023 [survey](#)¹⁰ revealed the following with respect to carers of older people:

- 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
- 44 % said that their caring role had impacted negatively on their own health, and

⁵ Royal Commission into Aged Care Quality & Safety; Final Report: Care Dignity and Respect, 2021 [Final Report | Royal Commissions](#)

⁶ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC), 2022 [Disability, Ageing and Carers, Australia: Summary of Findings, 2022 | Australian Bureau of Statistics \(abs.gov.au\)](#)

⁷ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC), 2018 [4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018 \(abs.gov.au\)](#)

⁸ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC), 2022 [Disability, Ageing and Carers, Australia: Summary of Findings, 2022 | Australian Bureau of Statistics \(abs.gov.au\)](#)

⁹ Carers Australia consultations for the Department of Social Services for the National Carer Strategy, 2024, <https://www.carersaustralia.com.au/national-carer-strategy/>

¹⁰ University of Canberra, 2023 Carer Wellbeing Survey, Data extracted from data sheets for the 2023 Carer Wellbeing Survey and available on request to Carers Australia. [2023-CWS-Report.pdf \(carersaustralia.com.au\)](#)

- only a third said they had accessed respite in the last 12 months with a third reporting poor satisfaction with their access to respite (this was a quarter for those who were caring for someone with dementia).

With some slight variations, these results are consistent with feedback from former surveys.

Respite for carers of older people is mainly dependent on what is delivered by the aged care system and comes fairly and squarely within the province of the of the portfolio responsible for aged care. While carers can be referred to respite services by the Carer Gateway, the aged care system is responsible for funding these services and securing adequate supply.

The supply of respite has always been a contentious issue and in recent years we have witnessed a decline in respite access, with access to Commonwealth Home Support Program respite declining by 34% between 2019-2020 to 2022-23 (the latest data available to us) and the number of respite providers by 17%. Residential respite access has increased moderately over the same period, but it is not always an attractive option for carers and those they care for. We also receive reporting that access to genuine respite in residential facilities is limited as allocations of respite beds are often used as a stop gap while waiting for a permanent residential position (this includes try before you buy).

Royal Commission into Aged Care Quality and Safety recommendations with respect to carers

Respite for carers was a focus point of the Royal Commission.
In its Final Report the Commission 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.*¹¹

Indeed, in its first recommendation the Commission provided a definition for a new Aged Care Act which was carer inclusive. The new Act is defined 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

¹¹ Royal Commission into Aged Care Quality and Safety, Final Report, Executive Summary, page 103 [Aged Care Quality and Safety | Royal Commissions](#)

(b). supports, including respite for informal carers of people receiving aged care¹⁰.

It specifically referenced the Statement for Carers in the *Carer Recognition Act 2010* as a foundation for the new Aged Care Act:

[T]he system of entitlements under the new Act should extend not only to people receiving aged care, but also to those seeking it. They should also extend to family members and friends who undertake significant carer-related responsibilities—people we refer to as ‘informal carers’. The inclusion of entitlements for informal carers in the new Act is consistent with the principles expressed in the Carer Recognition Act 2010 (Cth). However, unlike the Carer Recognition Act, the new Act should provide means of enforcing those entitlements¹⁰.

Under Recommendation 2, which deals with the rights of older people receiving aged care, recommendation 2(d) stipulates:

(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.¹²

Under its Key Principles recommendations, Recommendation 3(ii) stipulates that:

(I)nformal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need¹³.

The Commission went on to make a number of recommendations with specific application to a range of respite services, training and education for carers, counselling, and navigation services enabling direct referral and information sharing for informal carers between My Age Care, care finders, assessment services and the Carer Gateway.

The Bill

While the Bill has largely delivered on the recommendations of the Commission with respect to establishing the rights of older people accessing aged care services, we are very disappointed that it failed to incorporate the rights for carers proposed by the Commission.

¹² Ibid, page 206

¹³ Ibid. page 207

Despite our involvement in many consultations around the Exposure Draft, including a [submission](#)¹⁴ by Carers Australia and the joint [submission](#)¹⁵ of National Aged Care Alliance (NACA) consumer bodies, the Bill barely makes reference to carers.

Carers are **not** mentioned in the Objects of the Act.

It bestows no rights directly upon carers. The closest it comes to is:

*An individual has a right to have the role of persons who are significant to the individual, including carers, visitors and volunteers, be acknowledged and respected.*¹⁶

And then a token gesture of appreciation:

*The Commonwealth aged care system:
6(c) recognises and supports the important role of advocates, carers, volunteers and visitors in improving individuals' experiences of the Commonwealth aged care system.*¹⁷

This is followed by the extraction of a single principle out of eight under the Statement for Carers in the *Carer Recognition Act 2010*:

*The Commonwealth aged care system recognises the valuable contribution carers make to society, consistent with the Carer Recognition Act 2010, and carers should be considered partners with registered providers who deliver funded aged care services.*¹⁸

There are only three references to respite in the Bill, which the Royal Commission identified as a priority throughout its report and recommendations, and these only relate to fees and charges for residential respite.

¹⁴ Carers Australia, Response to the Australian Government Department of Health and Aged Care – Consultation on the Exposure to Draft of the New Aged Care Act, 2024

¹⁵ National Aged Care Alliance Aged Care Act Exposure Draft Joint submission National organisations working with older people and carers, 2024

¹⁶ AgedCare Bill 2024, Definitions and Key Concepts, Key Concepts 2, Key Concepts, Division 1, Section 23 (11) [ParlInfo - Aged Care Bill 2024 \(aph.gov.au\)](#)

¹⁷ Ibid, Chapter 1, Part 3, Division 2 (6)

¹⁸ Ibid, Chapter 1, Part 3, Division 2 (7)

In summary

While we understand that, given the short timeframe for consultation on the Bill and the sense of urgency that the Act needs to come into force to address the rights and quality of care for older Australians, there will be little opportunity for major revision.

However, we hope at the very least that the Committee will mention the failure of the Bill to incorporate the recommendations of the Royal Commission in relation to carer inclusion in the Act, given the immense contribution carers make to the aged care economy and to the people they care for; often while failing to get much needed support and meaningful recognition for themselves.

Carers Australia Recommendation

Against this background, and noting that there are likely to be a number of aspects of the Act that are likely to produce unintended consequences and omissions that will be revealed in the first years of its operation, we recommend that an independent review of the operations of the Act should be undertaken within three years of its implementation as opposed to six months after the fifth anniversary of the Act as recommended in *Section 601* of the Bill.

We do think that the failure of the Bill to incorporate the needs of carers as identified by the Royal Commission and the impact of that failure on the contribution carers make to the quality of care available and the sustainability of aged care will raise issues of concern in such a review.

A snapshot of Australia's carers

There are three million¹⁹ carers in Australia, with approximately two thirds caring for someone under the age of 65⁵. Women make up 54% of all carers and 67.7%⁵ of primary carers. Carers can be any age, 13% of carers are 24 years of age and younger⁵, and 35.7% of carers are 65 years and older⁵. Within the First Nation's population, 14% of the Aboriginal and Torres Strait Islander population identify as carers²⁰ and 30% of carers were born overseas⁵. In 2022, 38.6% of primary carers also identified as living with a disability⁵.

Being a carer is a constrained choice and a significant commitment that impacts many aspects of a carer's life. Results from the [Caring for others and yourself:2023 Carer Wellbeing Survey \(Survey\)](#)²¹ identified that compared to the average Australian, carers were almost twice as likely to report low wellbeing, are almost 1.4 times more likely to have psychological distress, are 2.5 times less likely to have good/excellent health outcomes and are 1.4 times more likely to experience significant financial distress. Compared to the national average of 16% of Australians, 40% of primary carers and 30% of non-primary carers relied on a government pension or allowance as their main source of income⁵.

The annual economic value provided by carers has been valued by Deloitte Access Economics at \$77.9 billion per year²².

Data from the Australian Bureau of Statistics (ABS) reports that approximately three in five (60.5%) of the 5.3 million people living with disability in Australia receive assistance with at least one activity of daily living, with 71.6% receiving assistance from informal carers²³. Informal carers often provided support with communication, mobility, and reading or writing related tasks.

¹⁹ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

²⁰ Australian Bureau of Statistics, Census 2021

²¹ Caring for others and yourself:2023 Carer Wellbeing Survey (Survey)

²² Deloitte Access Economics (2020), The value of informal care

²³ Australian Bureau of Statistics 2022