

Submission to the Office of the Inspector-General of Aged Care: 2024 Progress Report on the Implementation of the Aged Care Royal Commission Recommendations

March 2024 Introduction

Carers Australia welcomes the opportunity to provide input to the Review.

While we have an interest in all the issues raised for comment and in a number of other recommendations of the Royal Commission, our particular focus in this submission is the recommendations directly relating to carers. In this context, we have primarily focused on the new Aged Care Act and on respite, noting that respite has been nominated as one of the nine areas of particular interest. However, we have touched on other recommendations in relation to carers as well.

Recommendations of the Royal Commission into Aged Care Quality and Safety with Respect to Carers

Using carer data from the 2018 Survey of Disability, Aged and Carers (SDAC), in 2020 Deloitte Access Economics valued the replacement cost of substituting unpaid care with paid care at \$77.9 billion dollars (or 2.2 billion hours of care per year).¹ 35% of these carers were caring for someone over the age of 65, and 25% were themselves over the age of 65²³.

The Royal Commission recognised both the value of carers to the sustainability of the aged care system and the need for these carers to access support services to help them weather the often very high demands of their caring roles. It also acknowledged that the system had let carers down over the years.³

It went on to make several recommendations with respect to carers. Key recommendations are referenced below.

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

² Extracted through Table Builder from the Australian Bureau of Statistics, Survey of Disability, Ageing and Carers, 2018 [accessed here](#)

³ Royal Commission into Aged Care Quality and Safety, 2021, Final Report: Care, Dignity and Respect, Executive Summary, p.103 [accessed online](#)

1) Royal Commission recommendations pertaining to the Foundations of the Aged Care Act

With respect to the **foundations of the Aged Care Act**, the Commission made a number of recommendations in relation to carers.

Recommendation number	Recommendation	Progress to date
Recommendation 1:2	<p>The new Act should define aged care as:</p> <ul style="list-style-type: none"> 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 	The Exposure Draft of the New Aged Care Act does not provide a definition of aged care
Recommendation 2: Rights of older people receiving aged care	d. for 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	The Exposure Draft of the New Aged Care Act does not bestow this right upon carers
Recommendation 3: Key principles	ii. Informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need	The Exposure Draft of the New Aged Care Act does not incorporate this principle

In its final report, but not in the recommendations, the Commission also 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 entitlements.⁴ (emphasis added)

One of the principles in the *Carer Recognition Act* (2010) is referenced in the Exposure Draft with respect to the Statement of Principles:

*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.*⁵

However, to the best of our knowledge, this principle is non-binding and not enforceable – as is the case for the *Carers Recognition Act*.

Progress

In summary, with respect to the Foundations of the Act, the Exposure Draft does not incorporate the recommendations of the Royal Commission with respect to carers.

2) Commission recommendations with respect to specific carer support services

The Commission went on to make a number of recommendations with specific application to a range of respite services, training and education, 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.

Respite

ACRC Recommendation 32: Respite supports category

- Implementation of a respite supports category within the aged carer program that:
 - a. Supports the availability of respite for carers of older people earlier and more often to maintain their wellbeing
 - b. Provides a greater range of high-quality supports in people’s homes, in cottages and in purpose built facilities
 - c. Provides people with up to 63 days respite per calendar year
 - d. Is grant funded with a potential capital component.

⁴ Royal Commission into Aged Care Quality and Safety, 2021, Final Report. Vol.3A, page 6 [emphasis added] [accessed online](#)

⁵ Exposure Draft of the Aged Care Bill 2023, Chapter 1, Part 3, Division 2 Section 22:7 [accessed here](#)

Progress

Respite is highly valued and needed by carers of older people.

Carers Australia in partnership with the University of Canberra, undertakes an annual Carer Wellbeing Survey.

The results of the 2023 survey 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
- 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.⁶

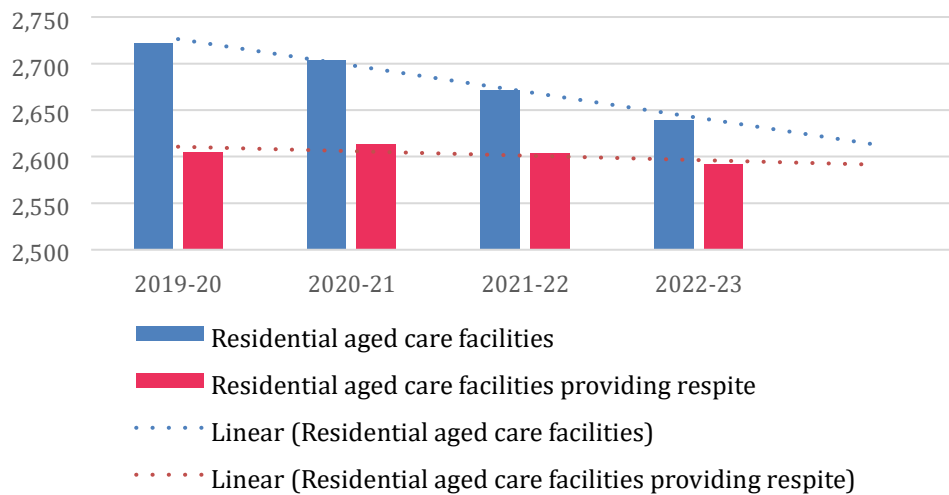
However, data validating activity within the respite space is patchy and often difficult to unpack, as the charts below based on data from the Department of Health and Aged Care's annual *Reports on the Operations of the Aged Care Act* illustrate.

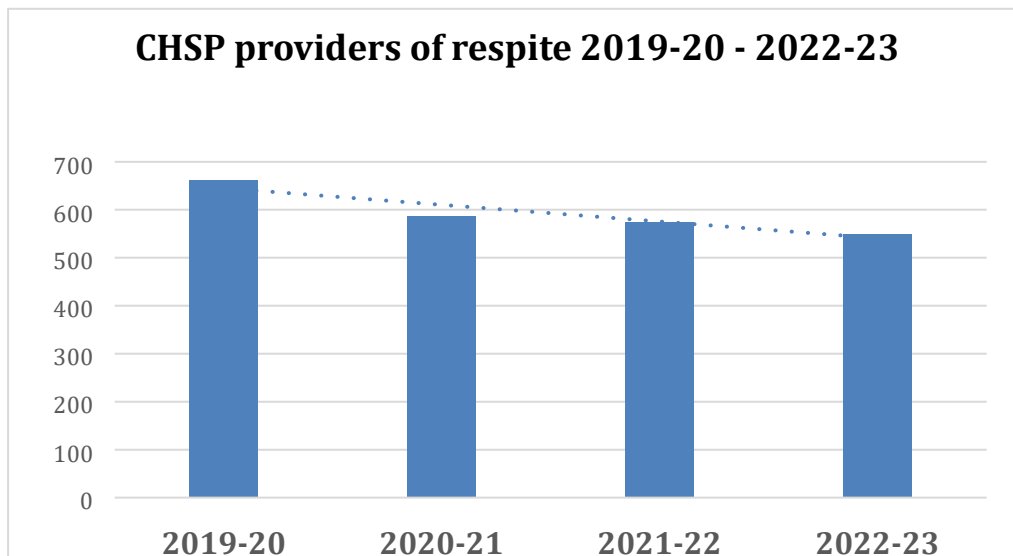
⁶ Data extracted from data sheets for the 2023 Carer Wellbeing Survey. Data available on request to Carers Australia.

Access to respite 2019-20 - 2022-23



Residential aged care facilities providing respite





Residential Respite

Despite the decline in the number of residential respite facilities, there has been a gradual increase in the number of people accessing residential respite since the introduction of the AN-ACC funding model in October 2022. However, the numbers were rising even before the new funding model equalized, to a large extent, the subsidies for permanent residents and respite residents.

In addition, the number of people entering into permanent residential care shortly after accessing respite remains high, suggesting that respite is being used by potential permanent residents on a ‘try before you buy’ basis or for the purposes of taking a permanent place while they are sorting out their contractual and other arrangements.

Short transitions from respite to permanent residential care have grown steadily from 56% in 2019-2020 to 60% 2022-23. This trend has been growing for a long time. An Australian Institute of Health and Welfare report on *Pathways in Aged Care* released in 2023⁷ identified the number of residential respite of users exiting respite and entering permanent residential aged care on the same day between 2010-11 and 2019-20, showing a steady increase from 26% in 2010-11 to 52% in 2019-20. While we understand why people would find it useful to access residential aged care for these purposes, it is not what respite accommodation was intended for and it blocks access sought for the purposes of giving carers respite from caring, which may be essential many carers to keep providing care in the home.

Certainly feedback from Carer Gateway providers is that is a difficult and lengthy process to find access to residential respite in the period carers need it. The situation is particularly bad in outer regional and even some inner regional locations.

Community Respite

In contrast, access to community respite under the Commonwealth Home Support Program (CHSP) has declined steadily since 2019-20; noting that we have not been able to find CHSP numbers before this date. In addition, CHSP respite takes a number of different forms, embracing:

⁷ AIHW, *Pathways in Aged Care*, [accessed here](#)

- Centre-based day respite
- Residential day respite
- In-home day respite
- In-home overnight respite
- Host family day respite
- Host family overnight respite
- Cottage respite (overnight community)
- Mobile respite

There is no breakdown of these sub-categories in the *Reports on the Operations of the Aged Care Act* or any other sources we can find.

At a broad level, the decline in the number of people accessing CHSP is mirrored in the decline of CHSP providers of respite. This is against the background where, in 2021–22, \$18.9 million was provided to eligible CHSP respite care providers to increase flexible and centre-based respite services to support an additional 8,400 CHSP clients.

The question is: are CHSP respite providers shrinking through lack of demand or is demand shrinking through lack of providers? It also raises the questions of the adequacy of subsidies and the affordability of co-payments for CHSP respite. Either way these trends are disturbing because dedicated community respite is often the form of respite most favoured both by carers and those they care for. It provides more flexible respite opportunities, for shorter terms, and in more familiar environments. Most residential facilities won't take on respite clients for under four weeks, and entering into residential respite can be a very confronting experience for older people, especially those with dementia.

Certainly there have been developments in train for respite improvements for carers of people with dementia (see below). However, while the focus on dementia is understandable, carers of people with other conditions also require and deserve more of a policy and programs spotlight on their needs in the reform process.

Without such information, it is very difficult to gauge what is happening across the sector.

Supports for people with dementia and their carers

Recommendation 15:1

- By 1 January 2023, the Australian Government should establish a comprehensive, clear and accessible post-diagnosis support pathway for people living with dementia, their carers and families.

This should involve:

- a. providing information and advice on dementia and support services, including the aged care system
- b. facilitating access to peer support networks
- c. providing education courses, counselling and support services

d providing assistance with planning for continued independent living and access to care, including regular and planned respite for carers (emphasis added)

Progress

Support for people with dementia and their carers is one area where some progress has been made, but it is still early days.

The development of a National Dementia Action Plan has been a very inclusive process through ongoing Departmental engagement with relevant peak organisations, providers of dementia services and opportunities for feedback from people with lived experience. The needs of carers of people with dementia are embedded in the principles and the Department is piloting innovative and, for many carers, a better targeted respite support model with Dementia Services Australia.

Complementing other supports for people with dementia, the Improving Respite Care for People with Dementia and their Carers program commenced in 2022–23. The program aims to increase supports for carers of older people, particularly those caring for a person living with dementia at home, through access to dementia-specific respite care and training. In 2022–23, the program supported a total of 254 participants (and includes people with dementia and carers) across 25 programs delivered nationally. However, according to AIHW data, there were between 137,600 and 354,200 informal carers of people with dementia who live in the community in 2022. According to the 2018 Australian Bureau of Statistics' Survey of Disability, Ageing and Carers, around 55% of carers of people with dementia were primary carers. The current reach of the new program is very small.⁸

Results for carers of people with dementia from the 2023 Carer Wellbeing Survey revealed that:

- With respect to support from My Aged Care –35.5% said poor access, 12.4% were equivocal, and 52% reported good access
- 64.9% said they had not accessed respite and 35.1% said that they had.
- Only 19% said they had access to carer training and skills courses.⁹

Aged care eligibility assessments and referrals

ACRC Recommendation 28:1(d)

3) By 1 July 2023, the Australian Government should replace the Aged Care Assessment Program and the Regional Assessment Services with one assessment process. That assessment process should:

- d. include an assessment of any informal carer's needs

ACRC Recommendation 42: Support for informal carers

The Australian Government should improve services and support for informal carers by:

⁸ Australian Institute of Health and Welfare, Dementia in Australia, last updated 21 September 2023 [accessed online](#)

⁹ Data extracted from data sheets for the 2023 Carer Wellbeing Survey. Data available on request to Carers Australia.

- a. linking My Aged Care and the Carer Gateway by 1 July 2022, so that informal carers need only use one system to secure respite care and the full range of information, training and support services available on both sites,
 - b. on and from 1 July 2022:
 - i. enabling direct referral and information sharing for informal carers between My Aged Care, care finders, assessment services and the Carer Gateway
 - ii. providing accurate and up-to-date information on My Aged Care about the range of supports locally available to informal carers, including training, education, counselling, respite, income support, and access to the Carers Hub network (once established)
 - c. on and from 1 July 2023:
 - i. requiring My Aged Care, care finders and assessment services to identify the primary informal carer when assessing a person for aged care.
 - ii. enabling care finders to refer the primary informal carer to assessment services for assessment for, and access to, formal respite care and other supports available.
 - iii. establishing and funding a community-based Carers Hub network enabling direct referral and information sharing for informal carers between My Aged Care, care finders, assessment services and the Carer Gateway.
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Progress

- With respect to carer inclusion in aged care eligibility and planning assessments, the new single assessment system has not yet commenced. We are aware of the pilots which have been undertaken and have been informed that assessors involved have been alerted to the need to gauge carers' needs for support and point them to the Carer Gateway. However, to the best of our knowledge, this does not involve warm referrals. We are unaware of any data in relation to the number of carers who have been referred to the Gateway during the pilots.
- With respect to My Aged Care, carer supports are identified along with links to carer advice and some short case studies. But the information is scant and links to the Carer Gateway substitute for more detailed information. For many inquiries, My Aged Care refers the carer to the Gateway site and the Gateway, in turn, refers them to My Aged Care. As for the Care

Finders Program, it places limitations on access to that assistance if the person seeking aged care has a carer. We have had no feedback on the program from carers.¹⁰

- The Carers Hub was not supported in the 2021 Australian Government Response to the Final Report of the Royal Commission into Aged Carer Quality and Safety. The logic behind this is that the Carer Gateway is already a hub for carer support services. How successful Gateway providers have been in navigating between carer supports, the aged care system, the disability and the health systems has not yet been subject to review.

Summary

With respect to carers and the implementation of the Aged Care Royal Commission's recommendations, the results to date have been very limited. Many of the Commission's timelines for the implementation of its recommendations were very ambitious and it has taken considerably more time than the Commission anticipated to bed them down into operational practice. In addition, inter-related recommendations have demanded staggered timelines.

Having said this, as far as carers are concerned, the focus on carer supports has been limited; confined largely to the introduction of funding adjustments to residential respite and the start-up dementia community respite program.

A particular disappointment is that no legal rights are conferred upon carers in the Exposure Draft of the New Aged Care Act, although we have yet to see the final form of the Bill.

In responding to systemic issues in aged care, it is very hard to draw conclusions and measure reform progress in the absence of good data. With respect to respite, the publicly available data on residential respite in the annual *Reports on the Operation of the Aged Care Act* is considerably

better for residential respite than for community respite, although it is only broken down on a state and territory basis rather than a regional basis. We have noted the decline in CHSP funded respite, but there is no data on the distribution of these services or the sub-set of CHSP respite services available and who uses them.

In the interest of transparency and evaluating the impact of changes, we strongly recommend that the Inspector General should require the Department to publish more comprehensive data with respect to respite. That data should include:

- **Access to both residential and CHSP respite on a Modified Monash Model (MMM) classification basis and be accompanied by a distribution map.**
- **CHSP respite access should be broken down into respite sub-categories and broken down by providers of these different forms of respite and the number of people accessing them.**
- **Any data the Department holds on carers with respect to groups included in the aged care diversity framework.**

¹⁰ Department of Health and Aged Care, My Aged Care: Help from a care finder, [accessed here](#)

- **The number of carers of older people interviewed and the number referred to the Carer Gateway by assessors under the new eligibility and planning assessment model.**

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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