

28 March 2025

Office of the Inspector-General of Aged Care
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Carers NSW welcomes the opportunity to provide a submission to the Inspector-General of Aged Care to inform the 2025 Progress report. Carers NSW commends the Australian Government on their commitment to improving the quality and safety of aged care services for all Australians who are ageing and their carers through the development and passing of the new Aged Care Act. However, Carers NSW has significant concerns about the roll out and implementation of aged care reforms, given the lack of focus on and inclusion of carers in the design of the new aged care system. Furthermore, given significant impending changes, including the roll out of the Support at Home Program from 1 July 2025, Carers NSW has significant concerns that new arrangements are still in development and there is a lack of clear information to support transition readiness for people who are ageing, their carers, service providers and the sector more broadly.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Thank you for accepting our submission. For further information, please contact Melissa Docker, Manager Policy and Development, at melissad@carersnsw.org.au or by calling (02) 9280 4744.

Yours sincerely,



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CEO
Carers NSW

Introduction

Carers NSW thanks the Committee for the opportunity to provide feedback on the progress of the implementation of recommendations from the Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission). Carers NSW welcomes this landmark opportunity to strengthen the rights and safety of people accessing aged care services. The establishment of a new aged care system also provides an opportunity to improve recognition and support for family and friend carers. Carers are vital in assisting, supporting and advocating for people who are ageing and are often active participants in the aged care system themselves. However, Carers NSW is concerned that despite clear recommendations from the Aged Care Royal Commission which focused on improving identification, recognition and support for carers, they have continued to receive limited recognition and inclusions in the new Aged Care Act and associated rules and policies.

Carers NSW believes in the importance of autonomy and self-determination for people who are ageing and is supportive of policy and practice that facilitate their independence and meaningful participation in community life. Carers NSW recognises that not all people who are ageing receive informal support or would identify as having a 'carer'. However, the 2022 Survey of Disability, Ageing and Carers (SDAC) found that of the approximate 1.7 million people who are ageing who require assistance with at least one everyday activity, 71.6% (approximately 1.2 million) reported receiving some assistance with everyday activities from informal supports, most commonly their spouse who is often ageing themselves.¹

The Aged Care Royal Commission identified the need for improved supports for carers as the aged care system currently provides 'reactive' and 'inadequate' support that comes only when carers have reached crisis point.² Its Final Report included a number of recommendations focusing on embedding recognition and improving support for carers under a new Aged Care Act.³ Carers NSW believes that to date, proposed and established changes do not go far enough in supporting the Aged Care Royal Commission's vision as it relates to carers.

While Carers NSW is pleased to see the inclusion of the Commonwealth (Cth) *Carer Recognition Act 2010* within the new Aged Care Act, Carers NSW is disappointed that recognition of rights for and reference to carers is limited in the new Act despite the recommendations of the Aged Care Royal Commission. Furthermore, Carers NSW also commends the Australian Government on increased investment in respite and Carer Gateway integration and improved whistleblower protections for carers, however Carers NSW believes greater structural change is required to support carers to access adequate and high quality services and supports.

Embedding carer recognition

The Aged Care Royal Commission highlighted the significant role of carers within the aged care system and the need for increased and improved support for carers to ensure the sustainability of the system.

"Family, friends and community are a crucial part of the aged care system. They are integral to the wellbeing of older people, and are essential to efforts to try to ensure that older people receive high quality and safe care. They nurture, they support, they care, they advocate and they speak up when something is not right. They are the unsung heroes..."

¹ Australian Bureau of Statistics (ABS) (2024), *Disability, Ageing and Carers, Australia: Summary of findings, 2022*, New South Wales Tables, Canberra.

² Royal Commission into Aged Care Quality and Safety (RCAC) (2022), *Final Report – Care, Dignity and Respect: Volume 1*, 2021. Canberra.

³ Ibid.

... Early investment in, and support for, informal carers helps to maintain the capacity of carers to support older people. Informal carers may help prevent decline in older people, which may delay or avoid older people's entry into the formal aged care system—saving government costs. More fundamentally, early intervention should provide support to those who need it, when it is needed and ideally before a crisis develops..."

- Royal Commission into Aged Care Quality and Safety, Final Report, Volume 3A⁴

Furthermore, to ensure improved support for carers within a new aged care system, the Aged Care Royal Commission recommended that informal carers be embedded within the new Aged Care Act:

"Recommendation 1: A new Act

2. 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 3: Key principles

The new Act should:

- b. specify the following principles that should also guide the administration of the Act:*
 - ii. informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need"***

- Royal Commission into Aged Care Quality and Safety, Final Report, List of Recommendations⁵

Carers NSW was pleased to see carers recognised through reference to the Cth *Carer Recognition Act 2010* within the *Aged care principles* of the new Bill under 'An aged care system that values workers and carers'. However, Carers NSW is concerned that the recommendations of the Aged Care Royal Commission have not been adequately reflected in the new Aged Care Act, with limited mention of carers throughout the remainder of the Act. While additional rules and policy have provided opportunities to ensure the inclusion of carers in the implementation of the new Act, Carers NSW is concerned that reference to, or focus on, carers has been limited throughout subsequent legislation and policy. Carers NSW has significant concerns that a lack of visibility, rights and protections for carers within the new aged care system will result in ongoing significant negative impacts of caring on carers of older people.

Increasing supports for carers

The Aged Care Royal Commission also made a number of recommendations that aimed at improving support for carers within the aged care system, and other complementary service systems.

"Recommendation 42: Support for informal carers

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

- 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:*

⁴ RCAC (2022),

⁵ Ibid

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”

- Royal Commission into Aged Care Quality and Safety, Final Report, List of Recommendations⁶

Carers NSW recognises the Australian Government's commitment to improving support for carers of older people as well as carers more broadly. This includes through the ongoing funding of Carer Gateway, including additional funding to support improved integration with My Aged Care, and increased respite funding for carers of people living with dementia. However, Carers NSW has concerns that investment and reforms have not fully realised the vision of the Aged Care Royal Commission with respect to carers.

While the Australian Government has made a significant investment in improving integration between My Aged Care and Carer Gateway, ongoing constraints in information sharing between My Aged Care and Carer Gateway service providers continue to contribute to high administrative load for carers, with many still required to tell their story on multiple occasions to access support. Additionally, the need for an aged care assessment to enable access to residential respite, even where this is facilitated through Carer Gateway, continues to act as a barrier to accessing this service. This has been further exacerbated by significant wait times for aged care assessments.

Carers NSW has also been concerned that recommendations regarding the role of Care Finders in identifying and referring carers to appropriate supports is unable to be actualised within the established Care Finder model. Currently, people who are ageing may not be eligible for Care Finder services if they have a carer or family member supporting them. This is despite the fact that many carers continue to report significant difficulties navigating the aged care system and available services and supports. However, more importantly, the role of Care Finders as a key touch point for carer identification is unable to be fulfilled, with limited alternatives provided. Carers NSW believes that Care Finder or similar system navigation supports must be available to older people and their carers where this support is required. Furthermore, in lieu of Care Finders as identifiers of carers within the community, Carers NSW believes the Department must establish additional points of identification to enable referral to appropriate supports in a timely and effective manner.

Improving access to respite

Respite, or services that provide older people and their carers with breaks from caring arrangements, are essential in supporting carer health and wellbeing, carer participation in social and economic

⁶ RCAC (2022),

activities, and enabling the sustainability of caring arrangements. As such the Aged Care Royal Commission made a number of recommendations to strengthen and improve access to respite supports within a new aged care system.

“Recommendation 32: Respite supports category

From 1 July 2022, the Australian Government should implement a respite supports category within the aged care program that:

- a. supports the availability of respite for the carers of older people earlier and more often to maintain their wellbeing and to sustain the caring relationship*
- b. provides a greater range of high-quality respite support in people’s homes, in cottages and in purpose-built facilities*
- c. provides people with up to 63 days of respite per calendar year*
- d. is grant funded with a potential capital component in areas where supply is inadequate”*

- Royal Commission into Aged Care Quality and Safety, Final Report, List of Recommendations⁷

Carers NSW commends the Australian Government on increased investment in access to respite, especially for carers of people living with dementia, in response to the recommendations of the Aged Care Royal Commission. However, Carers NSW has concerns that the significant, ongoing barriers to respite for older people and their carers will likely be exacerbated through current aged care reforms as there has been limited focus on addressing systemic or structural barriers to respite access. Carers NSW believes that the following concerns must be addressed to enable the Aged Care Royal Commission’s vision of greater access to respite for older people and their carers:

- The lack of inclusion of a right to respite in the new Aged Care Act, with references to 63 days of respite funding not included in new aged care legislation and no alternative respite protections added.
- The design of the Support at Home Program and associated pricing guide which identify respite as one service type, when ‘respite’ may encompass a broad range of services such as in-home and community respite, cottage respite and day centre respite that vary in intensity, complexity and cost to deliver.
- The pricing approach for residential respite which does not adequately cover higher costs associated with residential respite or provide financial incentives to providers to provide this service type.
- The barriers to integration between My Aged Care and Carer Gateway, including limited information sharing between national service systems, which may create additional administrative burden for carers seeking additional respite through complementary service systems.

⁷ RCAC (2022),

Improving consultation processes

Carers NSW commends the Australian Government on its ongoing consultation with the community to inform the development of the new Aged Care Act and associated policy and programs. However, Carers NSW would like to stress that the high volume and short turnaround of aged care consultations at this time while well intentioned, is placing significant pressure on older people and their carers, as well as peak bodies and service providers. This may impact the level of participation for meaningful engagement, with many older people and carers views unable to respond or contribute to all consultations due to time and energy constraints, consultation fatigue and confusion about the purpose and scope of consultations.

While Carers NSW supports forthcoming reforms and efforts to consult with the sector on a range of areas, Carers NSW believes that a more coordinated consultation approach is needed across the Department and other aged care agencies to support effective consultation and limit strain on older people, carers and the sector. Ensuring that consultation materials are also accessible, with simple English and translated versions will also support engagement. Furthermore, Carers NSW would recommend, where possible, using a 'collect once, use multiple times' approach, with a focus on building on existing feedback through new consultations, instead of holding multiple, individual consultations.

Conclusion

Carers NSW commends the Department for providing an opportunity to provide feedback on the progress of the implementation of the recommendations of the Aged Care Royal Commission. Aged care reforms provide a key opportunity to strengthen the rights and safety of people who are ageing when accessing aged care services, as well as providing an opportunity to improve supports for family and friend carers. However, Carers NSW has significant concerns that poor or lack of implementation of carer focused recommendations from the Aged Care Royal Commission is likely to undermine the Royal Commission's vision of improving the quality and safety of aged care for not only people who are ageing, but also their carers as key supporters within the aged care system. Carers NSW believes that immediate action is needed to strengthen the rights and recognition of carers within the new aged care system, ensure their inclusion as partners in care and improve access to supports such as respite that promote carer wellbeing and the sustainability of caring arrangements.