

21 December 2023

Department of Prime Minister and Cabinet Independent Panel
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Carers NSW welcomes the opportunity to provide a submission to the Commonwealth Government COVID-19 Response Inquiry to improve government response measures in the event of future pandemics based on learnings from the COVID-19 pandemic. Carers NSW recognises the need to enact long lasting whole-of-government change to ensure future pandemic responses better support vulnerable groups, including family and friend carers.

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.

According to the Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers (SDAC), there are approximately 2.65 million carers in Australia.¹ For carers, COVID-19 has presented ongoing heightened challenges, with extended periods of isolation, reduction in formal health and social care services and an increased reliance on family and friend carers throughout the pandemic. Additionally, while carers were not generally identified as an at-risk group, they are more likely than the general population to be older, live with a disability and live with a long-term health condition,² placing them at higher risk of severe outcomes. Furthermore, they are more likely to encounter persons in vulnerable groups through the provision of unpaid care and support to their family members or friends.

In 2022, Carers NSW was commissioned by the NSW Ageing and Disability Commission Advisory Board to develop a report, titled *Preparing for the future: Learning from the impacts of the COVID-19*

¹ Australian Bureau of Statistics, (2019). *Survey of Disability, Ageing and Carers 2018*. TableBuilder Dataset. Canberra: Australian Government. Online available under: www.abs.gov.au.

² Australian Bureau of Statistics (2018), *Disability, Ageing and Carers, Australia: Summary of Findings*, available online at: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>. Viewed on 23 September 2022.

*response on older people, people with disability and carers in NSW (the Preparing for the future report),*³ that looked at the experiences of carers and the people they care for, government responses throughout the pandemic, and potential opportunities to improve preparedness for the future. This submission identifies areas relevant to carers which are still in need of attention by providing a summary of some key findings from the *Preparing for the future* report and insights from additional consultation work with carers conducted by Carers NSW to provide recommendations relevant to the Commonwealth Government. However, we urge the Prime Minister and Cabinet Independent Panel (the Panel) to review the report in its entirety.

Key impacts of COVID-19 responses for carers

The *Preparing for the future* report found that negative impacts experienced by carers and the people they care for were a result of difficulty accessing key support services, including residential aged care facilities, respite services, in-home and community aged care and disability supports, and mandated or self-imposed social isolation during the COVID-19 pandemic. Evidence indicated that carers and the people they care for maintained a higher degree of COVID-19 related social isolation, despite the easing of COVID-19 restrictions, due to the ongoing health risks experienced by people with compromised immune systems.

Additional negative impacts experienced by carers and the people they care for included:

- barriers accessing information and support, such as low digital literacy and digital access, language barriers, disability discrimination, and inconsistent or unclear communication from authorities.
- limited access to adequate personal protective equipment (PPE), accessible and affordable COVID-19 testing opportunities and timely vaccination.
- difficulties accessing essential items such as food, toiletries, and medication, particularly for carers caring for someone with dietary requirements or continence care.
- significant barriers for young carers completing their studies, due to inability to access necessary electronics or internet services to support their learning during COVID-19.
- increased concerns related to financial vulnerability and coercive control, and reduced access to safe alternative or short-term accommodation to escape violence.⁴
- difficulty visiting and providing care to the person they care for in hospital settings, with varying responses and policies across different NSW Local Health Districts (LHDs).
- heightened feelings of distress due to separation from family members in residential care, as well as reduced ability to monitor of the quality of care received by residents,⁵ and reduced level of care, as informal support was not available to complement formal services.

Carers NSW believes that a more integrated approach to planning and communication, and more inclusive and accessible public health information and initiatives are required to reduce the risk of adverse health and social outcomes for carers and the people they care for as the pandemic continues to evolve, and in future public health crises.

³ *Preparing for the future: Learning from the impacts of the COVID-19 response on older people, people with disability and carers in NSW (the Preparing for the future report)* available on the Carers NSW website: <https://www.carersnsw.org.au/resources/policy-and-research-resources?keywords=covid-19>

⁴ NSW Ageing and Disability Commission (2022).; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (2022) *The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability Issues paper*, available online at: <https://disability.royalcommission.gov.au/publications/impact-and-responses-omicron-wave-covid-19-pandemic-people-disability-issues-paper>.

⁵ Carers NSW (2020b).

Proposed actions

While the *Preparing for the future* report was aimed at understanding the impacts of COVID-19 and associated government responses, and identifying opportunities for improving pandemic responses in NSW, the findings indicated the need for a whole-of-government response, particularly due to complex and at times blurred jurisdictional issues. The *Preparing for the future* report, therefore, detailed 29 proposed actions, 18 of which relate to the Commonwealth Government, or involve shared jurisdictional responsibility. The proposed actions are summarised below, but for the complete list of these please see the *Preparing for the future* report.⁶

The proposed actions are grouped under five key areas:

- **Improve planning, consultation and leadership** – including to establish crisis protocols that trigger an integrated care sector response; and embed requirements to consult with bodies representing older people, people living with disability and carers.
- **Enhance information and messaging** – including to centralise and simplify official information sources and channels; embed accessibility and inclusive language requirements in communications; and support community outreach initiatives to ensure at-risk and hard to reach communities are aware of the services available to them.
- **Improve access to services and support** – including measures to manage priority access of at-risk groups to essential services during crisis periods; and expand digital literacy and access to older people, people living with disability and carers.
- **Address financial pressure** – including measures to support priority access to essentials and to support workplace flexibility that enables carers to continue to work where possible.
- **Enhance mental and physical health** – including measures to enable isolated people to remain connected; maintain community 'safe spaces' for older people, people living with disability and carers; and prioritise programs to help re-establish social connection as restrictions ease.

Carers NSW thanks the Prime Minister and Cabinet for the opportunity to provide feedback to the Commonwealth Government COVID-19 Response Inquiry. Carers NSW believes that the inquiry will enable improved understanding of the ongoing impacts of COVID-19 and provide opportunities for Government to improve policy and program responses to future pandemics for carers and the people they care for.

Yours sincerely,

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⁶ The complete *Preparing for the future: Learning from the impacts of the COVID-19 response on older people, people with disability and carers in NSW* report is available on the Carers NSW website: <https://www.carersnsw.org.au/resources/policy-and-research-resources?keywords=covid-19>