Preparing for the future

Learning from the impacts of the COVID-19 response on older people, people with disability and carers in NSW

Background paper, June 2023

Prepared by Carers NSW on behalf of the Ageing and Disability Advisory Board


ABORIGINAL
SPIRIT BEINGS

Contents

Executive summary

COVID-19 has had significant impacts on all NSW residents since the first case in NSW was confirmed in January 2020. However, many older people, people with disability and carers in NSW have experienced exacerbated and additional impacts as a result of their increased susceptibility and exposure to the virus, and their higher than average reliance on services and support networks that were disrupted by protective measures.

This background paper reviews key published evidence regarding the impacts of the COVID-19 pandemic on older people, people with disability and carers in NSW, in light of their increased risks of adverse outcomes. It examines the varied and common experiences of each target group, highlighting key outstanding issues that need to be addressed at present, and identifying opportunities to improve planning for future pandemics. It also reviews the key learnings and positive policy changes made in response to COVID-19, including reflecting on ongoing benefits to older people, people with disability, and carers in NSW.

Summary of proposed actions

Proposed actions for the NSW and Australian governments are included at the end of each section and are summarised below, with the relevant levels of government noted in brackets. While some of the proposed actions are clearly within the remit of one level of government, most require coordination between, and consistency across, NSW and Australian government responses. Levels of government rather than specific departments and agencies are identified to encourage integrated solutions that adapt to changes in portfolios and departmental structures following recent NSW and Federal Elections.

1. Planning, consultation and leadership

1.1 Streamline outbreak planning for residential care settings to include surge workforce, adequate supply of personal protective equipment and Rapid Antigen Tests, and monitoring for care quality (*NSW and Australian governments to action*).

1.2 Improve data collection and reporting on people with disability throughout the health care system (*NSW Government to action*).

1.3 Maintain the COVID-19 Disability Community of Practice (NSW) and Advisory Committee on Health Emergency Response to Coronavirus for People with Disability (Federal), and improve their channels to inform government policy making (*NSW and Australian governments to action*).

1.4 Embed requirements for consultation with bodies representing older people, people with disability and carers in NSW and Australian government pandemic policy directives (*NSW and Australian governments to action*).

1.5 Establish crisis protocols that trigger an integrated care sector response, involving representatives from the Australian Department of Health and Aged Care and Department of Social Services, as well as state and territory departments governing health care, disability, aged care and carer support services (*NSW and Australian governments to action*).

2. Information and messaging

2.1 Centralise and simplify official information sources and channels, with regard for consistency with Federal communications wherever possible (*NSW Government to action*).

2.2 Seek feedback from older people, people with disability and carers, including those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, on key information sources and formats to identify the most effective and inclusive communication methods (*NSW and Australian governments to action*).

2.3 Establish a short-term targeted grants program that enables cohort-specific peak organisations to rapidly expand their capacity to advise on, create and distribute targeted information during crisis periods (*NSW Government to action*).

2.4 Embed accessibility and inclusive language requirements into all public health communications frameworks (*NSW and Australian governments to action*).

2.5 Ensure mainstream public health helpline staff are able to provide accessible and cohort-specific information, rather than create separate information channels (*NSW and Australian governments to action*).

2.6 Consistently include key care service information (i.e. My Aged Care, NDIS and Carer Gateway contacts) alongside public health and mental health referral information in mainstream public health information (*NSW and Australian governments to action*).

2.7 Continue to provide and support community outreach initiatives to ensure at risk and hard to reach communities are aware of the services available to them (*NSW Government to action*).

3. Access to services and support

3.1 Provide more specific information for older people, people with disability and carers on how to determine and reduce risk in the home and community (*NSW Government to action*).

3.2 Maintain and monitor the implementation of the Partnerships in Care framework in residential aged care facilities (*Australian Government to action*).

3.3 Establish centralised, well communicated frameworks regarding visitation rights in hospital, mental health and residential disability settings (*NSW Government to action*).

3.4 Incorporate capacity within surge workforce planning for residential care settings to facilitate virtual connection with family members and friends (*Australian Government to action*).

3.5 Streamline and broaden access criteria for free PPE and Rapid Antigen Testing for older people, people with disability and carers (*NSW and Australian governments to action*).

3.6 Provide best practice guidelines to essential businesses, such as supermarkets, on managing priority access, ensuring that eligibility criteria and documentation requirements do not prevent at risk groups from accessing timely support (*NSW Government to action*).

3.7 Expand training modules on infection control and safe care in the home to carers (*Australian Government to action*).

3.8 Expand digital literacy and digital access support to older people, people with disability and carers (*NSW and Australian governments to action*).

3.9 Devise an evidence-based, stepped framework for maintaining priority access to health care, mental health care and aged and disability care services during crisis periods (*NSW and Australian governments to action*).

4. Financial pressure

4.1 Encourage workplaces to embed flexibility to allow older people, people with disability and carers to adjust their work location and hours where possible (*NSW and Australian governments to action*).

4.2 Prioritise inclusion of older people, people with disability and carers in the distribution of essential goods and services (*NSW and Australian governments to action*).

4.3 Expand financial security initiatives, including adjustments to income support, to include people on the Age Pension, Disability Support Pension and Carer Payment (*Australian Government to action*).

5. Mental and physical health

5.1 Maintain online delivery of social and recreational support, with digital access and digital literacy assistance, to enable isolated people to remain connected (*NSW Government to action*).

5.2 Maintain community 'safe spaces' with infection control and risk management measures in place, in which older people, people with disability and carers can use if their home environment is not conducive to social connection or economic participation (*NSW Government to action*).

5.3 Establish and communicate consistent policies to allow for the ongoing provision of essential care for people with disability and older people while in hospital (*NSW Government to action*).

5.4 Support carers to undertake and execute contingency plans in collaboration with service providers for if they become unwell (*Australian Government to action*).

5.5 Prioritise medium and longer term programs assisting older people, people with disability and carers to re-establish social connection as restrictions ease (*NSW Government to action*).

Introduction

This paper was developed for the NSW Ageing and Disability Advisory Board by Carers NSW, with funding from the NSW Department of Communities and Justice. It aims to examine the ways in which the Coronavirus (COVID-19) pandemic has impacted older people, people with disability and carers in NSW. Recognising that governments and service providers have taken many actions to improve access to resources and services during this unprecedented period, this paper seeks to identify areas which are still in need of attention.

COVID-19 has had significant impacts on all NSW residents since the first case in NSW was confirmed in January 2020. These impacts can be broadly categorised as direct – resulting from the virus itself – and indirect – resulting from the protective measures put in place by governments, communities and households to reduce the spread and severity of the virus.

Many older people, people with disability and carers in NSW have experienced exacerbated and additional impacts, both direct and indirect, due to their increased susceptibility and exposure to the virus, and their higher than average reliance on services and support networks that were disrupted by protective measures.

According to the Australian Bureau of Statistics 2018 Survey of Ageing, Disability and Carers (SDAC), approximately 1,287,800 NSW residents (16%) are aged 65 years and over, and 1,346,200 NSW residents (17%) live with a reported disability. An estimated 854,300 NSW residents (12%) care for an older person or a person with disability.[1] This means that a considerable proportion of the NSW population has likely experienced additional challenges relating to the pandemic.

Impacts of the virus

The Australian Government Department of Health and Aged Care has identified that older people and people with disability have a heightened risk of severe illness and mortality, often due to compromised immunity resulting from pre-existing conditions and/or ongoing treatment.[2] Specifically, data indicates that the majority of people who died as a result of COVID-19 were over 50 years old. Additionally, carers, while not generally identified as an at-risk group, are more likely than the general population to be older, live with a disability and live with a long-term health condition.[3]

While case and death data has been closely monitored throughout the pandemic, aggregated data indicating the relative prevalence of COVID-19 infection and mortality among older people, people with disability, carers and other cohorts of interest is challenging to source for NSW at the time of writing. This is particularly the case for mortality data. Table 1 provides an overview of publicly available data on COVID-19 deaths among the cohorts of interest since the beginning of the pandemic.

1. 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.
2. Department of Health and Aged Care (2022), *Risk factors for more serious illness*, available online at: https://www.health.gov.au/health-alerts/covid-19/advice-for-groups-at-risk/risk-factors-for-more-serious-illness. Viewed on 19 September 2022.
3. ABS (2018).

Table 1: Reported COVID-19 deaths* by target cohort

	Number of reported deaths (Australia)	Number of reported deaths (NSW)
NDIS participants	370**	30**
Non-NDIS participants	Not available	Not available
People with pre-existing chronic conditions	8,211	Not publicly available
People living with dementia	3,084	Not publicly available
People aged 60+	9,792	Aggregated data not publicly available
People aged 80+	7,015	Aggregated data not publicly available
People living in residential aged care facilities	4,099***	No longer publicly available (1,318 as at 16 August 2022)^
Aboriginal and Torres Strait Islander people	195 (Death rate 1.7 times higher than non-Indigenous people)	Not publicly available
People born overseas	5,156 (Death rate 1.6 times higher than those born in Australia)	Not publicly available
Total reported deaths	**12,545**	**5,454**^

In addition to being at risk of severe illness and mortality, early research indicates that older people, people with disability and carers may be at greater risk of developing 'long COVID'.[4] This is because factors heightening the risk of long COVID include being older, being female and having poor physical and mental health pre-COVID, including underlying conditions and diseases such as respiratory disease, hypertension and chronic heart or kidney disease.[5] Many older people, people with disability and carers live with one or more health or mental health conditions, and primary carers tend to be older and are more likely to be female.[6]

* The main source of data on COVID-19 deaths is monthly Australian Bureau of Statistics (ABS *COVID-19 Mortality in Australia)* articles, which report on the people registered with the ABS as having died "with or from COVID-19". Unless otherwise labelled, the data in this table is taken from the article reporting on registered deaths until 30 September 2022, extracted from https://www.abs.gov.au/articles/covid-19-mortality-australia-deaths-registered-until-30-september-2022 on 7 November 2022.

** Source: Department of Health and Aged Care, as at 1 November 2022. Extracted from https://www.health.gov.au/health-alerts/covid-19/case-numbers-and-statistics#cases-in-ndis-services on 7 November 2022.

*** Source: Department of Health and Aged care, as at 4 November 2022. Extracted from: https://www.health.gov.au/resources/collections/covid-19-outbreaks-in-australian-residential-aged-care-facilities#november-2022 on 7 November 2022.

^ Previously available at: https://www.nsw.gov.au/covid-19/stay-safe/data-and-statistics, extracted 16 August 2022.

^^ Source: NSW Health, as at 3 November 2022, extracted from: https://www.health.nsw.gov.au/Infectious/covid-19/Pages/stats-nsw.aspx on 7 November 2022.

4. Berry, E (2021), *Long COVID: What is it and what do we know about it?*, available online at: https://newsroom.unsw.edu.au/news/health/long-covid-what-it-and-what-do-we-know-about-it. Viewed 19 September 2022.

5. Delgado, C (2022), *Who's Most at Risk of Long COVID? New Study Finds Possible Key Factors*, available online at: https://www.verywellhealth.com/study-long-covid-risk-factors-6260268. Viewed 19 September 2022. Healthdirect (2022), *Understanding post-COVID-19 symptoms and long COVID*, available online at: https://www.healthdirect.gov.au/covid-19/post-covid-symptoms-long-covid. Viewed 19 September 2022.

6. ABS (2018).

Impacts of protective measures

SDAC data indicates that around 37% of older people in NSW, and around 56% of people with a reported disability in NSW, need assistance with at least one activity. Much of this assistance comes from 'informal providers', i.e. family and friend carers. Assistance is also commonly provided by formal services,[7] often delivered in the home. Reliance on access to family members and friends, especially those living elsewhere, and formal services, both in the community and in the home, posed significant problems for older people, people with disability and carers during stages of the pandemic where gathering and movement restrictions were in place. Additional precautions taken by these groups to avoid contracting or transmitting COVID-19 also restricted access to these essential networks.

The NSW Ageing and Disability Commission (ADC) and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (the Disability Royal Commission) have reported that COVID-19 heightened the risk of abuse, neglect and exploitation of adults with disability and older people.[8] Notably, preventative measures against the spread of COVID-19 led to the closure of community access, day program activities, and other in-person support services, a consequence of which was reduced oversight mechanisms that aim to protect older people and people with disability and a reduced ability to report abuse safely and away from the subject of an allegation.[9]

It has also been reported that COVID-19 public health orders gave rise to concerns related to financial vulnerability and coercive control, with the ADC receiving reports of older people and people with disability providing access to financial accounts to others and subsequently having their access to banking accounts and to other protective supports such as solicitors restricted.[10] Concerningly, the COVID-19 response also reduced access to safe alternative or short-term accommodation to escape violence.[11]

While mandated and self-imposed restrictions were a critical step to delay the spread of COVID-19 in NSW, especially among groups with a higher risk of contracting the virus and a higher risk of adverse outcomes, ahead of access to vaccines, in many cases they also increased the isolation of these groups from social support and formal services. The ways in which they were implemented and communicated also created confusion and stress for many.[12]

Access to adequate personal protective equipment (PPE), accessible and affordable COVID-19 testing opportunities and timely vaccination – all requirements for gaining access to many services and businesses, and to the community in general for some periods – was contingent upon timely and accessible supply, which was a challenge for all community members but additionally complex for many older people, people with disability and carers. This further limited their access to essential supports and in many cases increased their risk of contracting or transmitting COVID-19.

Consequently, while governments did implement protective measures and COVID-19 supports, they did not act quickly enough to protect vulnerable groups including older Australians in residential aged care and people with disability from COVID-19, or from the negative impacts of broader protective measures.

7. 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.

8. NSW Ageing and Disability Commission (2022) 2021-2022 *Ageing and Disability Commission Annual Report*, available online at https://www.ageingdisabilitycommission.nsw.gov.au/reports-and-submissions.html; 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

9. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (2022).

10. NSW Ageing and Disability Commission (2022).

11. Ibid.

12. Select Committee on COVID-19 (2022)

This paper

This paper reviews key published evidence regarding the impacts of the COVID-19 pandemic on older people, people with disability and carers in NSW, in light of their increased risks of adverse outcomes, both directly from the virus, and indirectly, from the community response. It examines the varied and common experiences of each target group, highlighting key outstanding issues that need to be addressed at present, and identifying opportunities to improve planning for future pandemics.

Method

Carers NSW consulted with the NSW Ageing and Disability Commission to identify the purpose and scope of this paper, and between June and September 2022 undertook a targeted review of published reports, briefings, government information and public health data focusing on the experiences of older people, people with disability and carers in NSW during the COVID-19 pandemic. Analysis and recommendations from the Royal Commissions undertaken on the aged care and disability sectors during this period, as well as by sector and consumer / carer peak bodies, including Carers NSW were a focus. Official NSW and Federal Government messaging and statistics issued in relation to the target groups were also examined.

Key publications were sourced from Carers NSW, Analysis and Policy Observatory (APO), the Royal Commissions into Aged Care Quality and Safety and into Violence, Abuse, Neglect and Exploitation of People with Disability, key peak body websites and NSW Health and Australian Government Department of Health websites. Each publication was reviewed and notes were taken according to each target group. Once all publications had been reviewed, notes were analysed to identify key themes. Key themes were noted and relevant points collated again according to each target group and theme. Key themes and points were then compared across target groups to identify common issues.

Proposed actions were developed with regard to recommendations from reviewed publications and existing actions taken by the NSW and Australian Governments. To develop themes, a table of all previous recommendations was drawn up from the reviewed publications. A timeline of all NSW and Australian government COVID-19 responses and initiatives in relation to older people, people with disability and carers was also created based on published media releases and official government responses to the respective Royal Commission reports. Both tables were compared to identity areas of ongoing concern in order to inform the proposed actions included in this paper.

Key themes are supported by cited evidence from the reviewed publications and data sources, and are outlined in the remainder of the paper. Learnings and positive policy initiatives are noted throughout, with theme-based actions proposed throughout and summarised in the final section.

Findings

Many of the challenges identified were common across the three target groups: older people, people with disability and carers, as outlined in the following sections. This indicates a strong need for an integrated approach to addressing current and future support needs across these groups, even though their respective service systems tend to be siloed. Learnings from the COVID-19 response indicates that improved and more efficient planning, consultation, and leadership between the NSW Government and Australian Government will aid in strengthening emergency responsiveness and reduce fatalities.[12]

13. Select Committee on COVID-19 (2022).

1 Planning, consultation, and leadership

Planning for the residential care sector

Analysis of the aged care sector's response to the pandemic has identified that a lack of prior planning for pandemics contributed to reports of compromised care quality in residential aged care facilities. The Australian Government under-anticipated and under-prepared for the pandemic and consequential outbreaks in residential care facilities, despite evidence that pre-dated the pandemic suggesting the residential care sector was already in crisis.[14]

In addition to significant numbers of outbreaks, cases and deaths in residential care facilities throughout the pandemic, insufficient pandemic planning and delayed responses to staff shortages, overreliance on casual workforce, PPE supply issues and demand for infection control training adversely affected the living conditions of many residents.[15] The Select Committee on COVID-19 Final Report (2022) details how residents were in some cases left without food, water, showering and toileting, due to lack of resources.[16] Paid care workers have also reported a lack of leadership within residential care facilities, with some workers expressing concern that policies and procedures for managing COVID-19 outbreaks were either not developed, were late to be developed, or were not communicated effectively to workers. Such issues increased worker stress and increased the risk of infection in and across residential care facilities.[17]

To mitigate the strain on aged care health workers as a result of the COVID-19 pandemic, the Australian Government Department of Health and Aged Care implemented the Temporary Surge Workforce Support program, where retired, part-time and under-employed health and aged care workers were utilised to support the health and aged care workforce.[18] While this initiative alleviated some of COVID-19 related workplace shortages, the program relied on a casual workforce, required that an aged care facility is suffering from direct impacts of a COVID-19 outbreak limiting its effectiveness in providing holistic support, and the program concluded in September 2022 while the COVID-19 pandemic was still ongoing.[19]

> ***"This is a terrible outcome for the community and is particularly tragic as some of these infections and deaths could have been avoided had the government responded more effectively to the pandemic.***
>
> **- Select Committee on COVID-19 Final Report**

As a temporary program it was therefore limited in its ability to provide sufficient support for the overburdened aged care and disability workforces amidst new variant waves of COVID-19.

Additionally, with visitation limited to minimise infection risk, and exacerbated by staffing shortages,[20] many residents experienced an increase in depression, anxiety and confusion.[21] Mental health impacts have also been experienced by carers due to concern about the level and quality of care received by their loved one and, in many cases, extended separation.[22] The Independent Review of the *Newmarch House COVID-19 Outbreak: Final Report*[23] highlighted the need for providers to develop and be ready to deploy a dedicated team of staff to act in the capacity of a Family Support Program to facilitate ongoing contact between residents and carers and to provide information and support to families and carers. It was also highlighted that there is a need to ensure clear protocols for the storage, decontamination and desired personal effects to family and carers following the death of a loved one.

13. Select Committee on COVID-19 (2022).
14. Ibid
15. Select Committee on COVID-19 (2020); Select Committee on COVID-19 (2022).
16. Select Committee on COVID-19 (2022).
17. Cortis, Natasha & van Toorn, Georgia. (2020). The disability workforce and COVID-19: initial experiences of the outbreak. 10.13140/RG.2.2.22871.21922.
18. Department of Health and Aged Care (2022), COVID-19 surge health workforce package, at https://www.health.gov.au/our-work/covid-19-surge-health-workforce-package. Viewed on 17 February 2023.
19. Ibid.
20. Select Committee on COVID-19 (2022).
21. Ibid.
22. Carers NSW (2020b), *The COVID-19 Pandemic: Challenges and opportunities for carers in NSW*, Carers NSW, North Sydney.
23. Gilbert, L. & Lilly, A. (2020) *Independent Review Newmarch House COVID-19 Outbreak [April-June 2020]: Final Report*, Department of Health, Canberra.

Inclusion of people with disability

While older Australians were a focus of government communication and initiatives from early in the pandemic, publications reviewed for this paper indicate that governments neglected to adequately consult with and plan for the needs of people with disability.[24] People with disability and the disability workforce were identified as being dangerously overlooked in the pandemic response, and faced increased risks associated with inadequate planning, safety protocols, and PPE provision. [25]

Many sources cite a lack of knowledge about people with disability, resulting from a lack of proper inclusion and consultation within the health care system, as a barrier to effective planning. One report describes how people with disability felt that precautionary measures recommended by health representatives highlighted the lack of awareness and understanding within the health system of the impact of disability; for example, requirements to self-isolate which were not practicable for those relying on external formal or informal support for basic daily needs.[26]

Furthermore, while data was collected and publicly reported regarding cases, hospitalisations and deaths among older people, inadequate data collection prohibited consistent reporting on the cases, hospitalisations and deaths of people with disability, outside of National Disability Insurance Scheme (NDIS) reporting requirements (see Table 1). This lack of reporting prevented responsive planning and indicated to many people with disability that their lives and experiences were not valued by health systems, governments or the general public.[27]

Continued improvement to 'disability literacy' in health care services, including adequate data collection and reporting and standing consultative mechanisms with an advisory role to decision makers, would enable a more rapid, informed response to the experiences of people with disability in future pandemics, as well as in continued spikes in cases and newly emerging variants.[28]

24. Select Committee on COVID-19 (2020).

25. Cortis, N. & van Toorn, G. (2020), *The disability workforce and COVID-19: initial experiences of the outbreak*, UNSW Social Policy Research Centre: Sydney.

26. Green C., Carey, G. and Dickinson, H. (2021), *Barriers and enablers in the development of a COVID-19 policy response for people with disability in Australia*, Centre of Research Excellence in Disability and Health: Melbourne.

27. Physical Disability Council of NSW (2022), *Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: The Impact and Responses of the Omicron wave of the Covid19 Pandemic for People with Disabilities Issue Paper*, Physical Disability Council of NSW: Glebe; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2022), *Statement of ongoing concern: The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability*, pp.1-4.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2021), *Public Hearing Report – Public Hearing 12: The experiences of people with disability, in the context of the Australian Government's approach to the COVID-19 vaccine rollout*, pp.1-130.

28. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2021).

Communication with government

The targeted review of published reports, briefings, government information and public health data focusing on the COVID-19 pandemic response reveals a need to improve communication, coordination and planning between the Federal Government, NSW Government and local government,[29] and between government and non-government bodies.[30] While the COVID-19 pandemic response was eventually mobilised, it is clear that there is a need for more efficient information sharing between Australian and state/territory governments, while the insights provided by peak bodies, local community organisations (such as culturally and linguistically diverse (CALD) community groups), and specialty disability and aged care support services, would have enabled better informed responses and provision of supports to be provided more holistically and effectively.

The NSW Ministry of Health was proactive in establishing the COVID-19 Disability Community of Practice, a consultative and information sharing mechanism for the Government to connect with the disability sector in NSW to facilitate communication and collaboration on COVID-19 response and messaging, and to hear about priority policy issues. However, while initially organised on a weekly basis, meetings have recently been reduced to monthly events on the grounds that issues faced by people with disability as a result of COVID-19 are resolved or are resolving, yet the pandemic is ongoing. Maintaining this stakeholder forum enables community advocates and local service providers to work collaboratively to improve health outcomes for people with a disability experiencing ongoing negative impacts from the COVID-19 pandemic.

In addition, an Advisory Committee on Health Emergency Response to Coronavirus for People with Disability was established at Federal level to monitor the risks of COVID-19 for people with disability. However, in NSW, health system policies and procedures remained largely determined at the local level, and higher-level decision making at NSW and Australian government level appeared not to reflect this body of evidence.[31] For example, this was reported to have been the case in relation to both the implementation of, and the relaxing of, movement and gathering restrictions as well as vaccination, testing and PPE requirements. In particular, the lack of consultation regarding the lifting of restrictions during the Omicron wave in early 2022 caused significant distress to those susceptible to severe illness.[32]

> ***"I have been very disappointed with both my State and Federal Governments response to carers during COVID. The only time the disabled got a mention and their carers, was when COVID hit the care homes. All they talked about was people who had their business effected, workers etc. Not realising carers were drowning in their roles. (Not unusual at the best of times)."***
>
> **- 2022 National Carer Survey respondent**

29. Select Committee on COVID-19 (2022).
30. NSW Ageing and Disability Commission (2022).
31. Children and Young People with Disability Australia (2022), *CYDA's response to the Disability Royal Commission's issues paper: The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability*, CYDA: Collingwood.
32. Physical Disability Council of NSW (2022).

Consultation with carers

The NSW *Carers (Recognition) Act 2010* requires all public sector agencies in NSW to consult with carers or bodies representing carers when developing policies that impact on carers. Equivalent Commonwealth legislation, the *Carer Recognition Act 2010*, obliges public service care agencies (including the NDIS and My Aged Care) to consult carers, or bodies that represent carers, when developing or evaluating care supports. While the pandemic precipitated a necessarily rapid public health response, and some proactive engagement with Carers NSW and other carer support organisations did occur, general population measures and care sector-specific measures were often announced without regard to direct and indirect impacts on carers.

Experiences from the COVID-19 pandemic should therefore inform future crisis planning within the health care system in order to ensure that carers are included in consultation, planning and messaging in relation to public health measures. Inclusion of carers in general health system planning, alongside older people and people with disability, and their representative organisations, is also recommended.

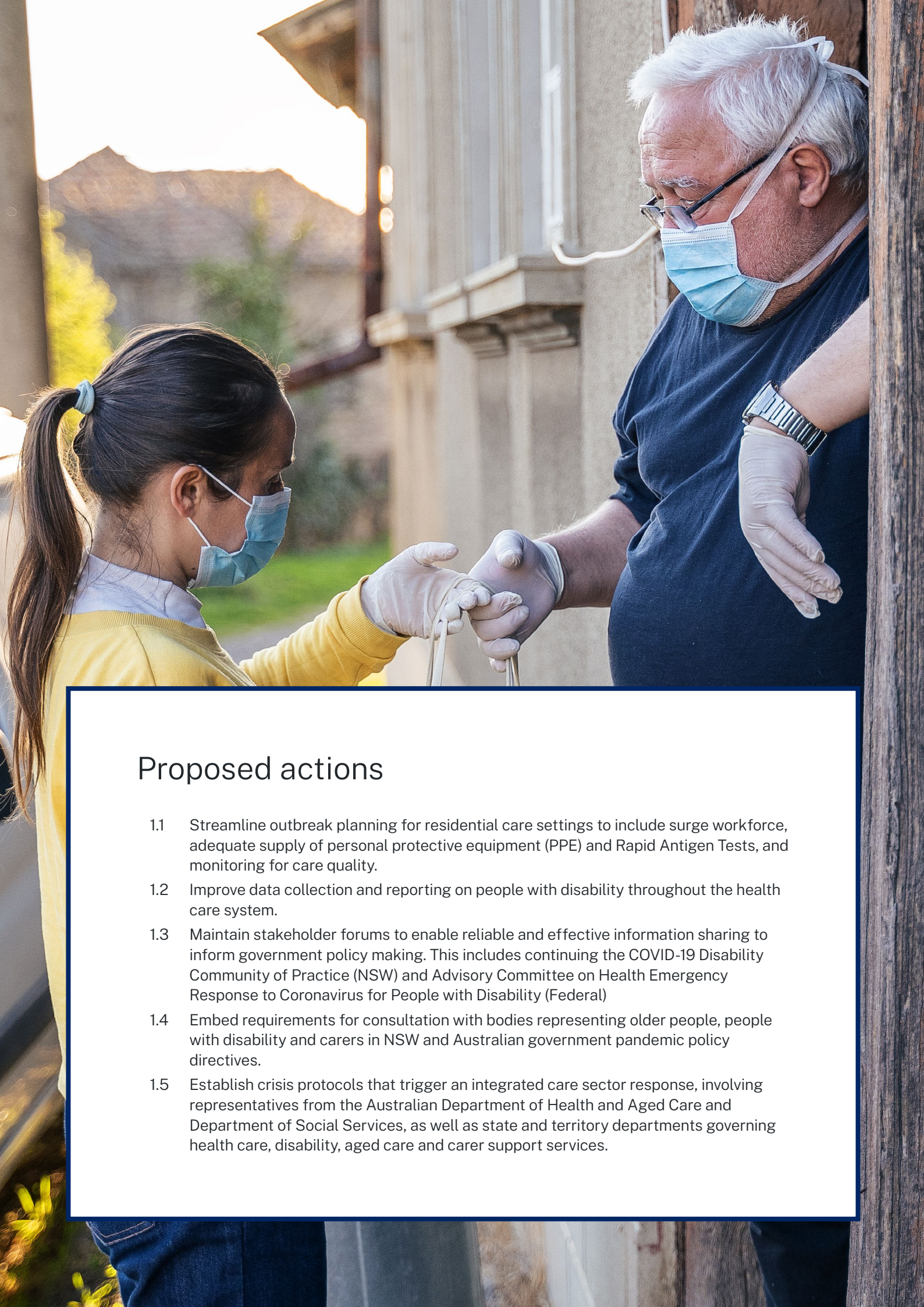
Coordinated leadership

Aged care, disability and carer support services are all predominantly funded and regulated by the Australian Government, and each system is administered independently. The 'siloing' of services for each of the three target groups, and the disconnection of these service systems from state-based public health responses led to a lack of clarity around who was responsible for addressing their needs. Confusion and duplication with respect to the roles of the NSW and Australian governments in setting and enforcing public health policy during the pandemic further complicated this, exacerbating concerns among older people, people with disability and carers, especially in relation to responses to outbreaks in residential care facilities.[33]

Coordinated responses at Federal level, and integration with public health decision making at state level and coordination with local governments, health and community services will allow for a more efficient and effective response in future. Following the Newmarch House outbreak, where concerns were raised about government agencies acting beyond their scope or power, NSW Health, in collaboration with aged care providers, the Commonwealth Department of Health and the Aged Care Quality and Safety Commission developed and published the *Protocol to support the joint management of a COVID-19 outbreak in a Residential Aged Care Facility in NSW*.[34] This provides one such example of creating defined roles to enable a whole-of-government response and enables transparency and accountability in coordinated responses.

33. Green et al (2021).

34. NSW Government (2022) *Protocol to support joint management of a COVID-19 outbreak in one or more residential aged care facility (RACF) in NSW*, NSW Government, Sydney.



Proposed actions

1.1 Streamline outbreak planning for residential care settings to include surge workforce, adequate supply of personal protective equipment (PPE) and Rapid Antigen Tests, and monitoring for care quality.

1.2 Improve data collection and reporting on people with disability throughout the health care system.

1.3 Maintain stakeholder forums to enable reliable and effective information sharing to inform government policy making. This includes continuing the COVID-19 Disability Community of Practice (NSW) and Advisory Committee on Health Emergency Response to Coronavirus for People with Disability (Federal)

1.4 Embed requirements for consultation with bodies representing older people, people with disability and carers in NSW and Australian government pandemic policy directives.

1.5 Establish crisis protocols that trigger an integrated care sector response, involving representatives from the Australian Department of Health and Aged Care and Department of Social Services, as well as state and territory departments governing health care, disability, aged care and carer support services.

2 Information and messaging

A key result of the lack of consultative, integrated planning and policy making was that public health information and messaging were unclear, inconsistent and non-inclusive. While Service NSW, NSW Health and the Australian Department of Health and Aged Care made a number of improvements to their information sources over time in response to feedback from sector peak organisations, issues persisted in the accessibility and content of public health information for older people, people with disability and carers.

Centralised information sources

Inconsistent and unclear information often resulted from constantly changing public health orders and varying measures across states and territories, as well as contradictory messaging between Australian and NSW Governments.[35] Together with sensationalist and critical media commentary, the absence of clarity and consistency resulted in anxiety and confusion among older people, people with disability, and carers, and limited access to the official information sources and support services available.[36]

> ***"There were different messages from the Prime Minister and the Premier. It was very confusing for me…I was confused by there being multiple chief medical officers. Who is in charge? Which government is in charge?"***
>
> **- Anthony Mulholland, NSW Council for Intellectual Disability**

35.Hofstaetter et al (2022).

36. Yates, I., Petrov, S., Wright-Howie, D., Brennan, P. and Swift, M. (2020), *Lessons of the COVID-19 crisis for Aged Care Reform: Submission 1*, COTA Australia: Barton ACT.

Accessible information sources

Research into the experiences of older people, people with disability and carers has indicated that these groups were often unable to access important public health information throughout the pandemic. With regard to accessibility, the main issues were being able to locate the right information at the right time, and the absence of tailored information in plain language and accessible formats, such as Easy Read publications, relay services, captioning, large print and Auslan.[37]

Particular concerns experienced by these groups, for example, vaccine hesitancy, especially where there were conflicting views within households, also required tailored content and framing, rather than just 'translation' into plain language. Furthermore, messaging and key information provided in English also needed to better accommodate differing literacy levels, by reducing medical jargon where possible, providing information in clear and simple language, and ensuring all information is available in Easy Read formats.

There was also a need for key information to be communicated in community languages and Aboriginal and Torres Strait Islander languages, including through trusted communication methods for these communities, such as through word of mouth and hard copy translated materials.[38] These did develop over time, with the NSW Government in particular delivering a large amount of audio-visual content in multiple languages in collaboration with culturally and linguistically diverse (CALD) communities and creating targeted publications and videos for people with disability during the Omicron wave.

> ***"When governments remind us about individual responsibility regarding COVID management, they need to keep us regularly informed. Older people are very responsible as we have shown this during this difficult COVID time. One role of governments is to keep us safe."***
>
> **- First Nations respondent, The Council on the Ageing NSW (COTA NSW)**

37. Carers NSW (2020b)Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020), *Statement of concern: The response to the COVID-19 pandemic for people with disability*, pp.1-6.
Kavanagh, A., Carey, G., Dickinson, H., Llewellyn, G., Bonyhady, B. and Trollor, J. (2020b), *People with Disability and COVID-19*, Centre of Research Excellence in Disability and Health: Melbourne.
38. Carers NSW (2020b).

Targeted content

While older people were often highlighted in official public health messaging, people with disability and carers consistently reported feeling overlooked and unable to confidently interpret public health advice and apply it to their own situation. This included difficulty finding tailored support information and evidence-based advice regarding levels of risk and recommended precautionary measures.[39] There was considerable confusion and anxiety in the community as a result, especially regarding:

- how and where to access appropriate support
- what regulations and restrictions applied to care service environments
- how to safely care for someone with COVID-19, or organise alternative care if the carer contracted COVID-19.[40]

> ***"Don't know where to go for help. Unable to arrange respite care. If you do get to talk to someone they always seem to be in a rush and don't get back to you anyway. Many changes with our My Aged Care Provider."***
>
> **– 2022 National Carer Survey respondent**

Over the course of the pandemic, targeted information pathways became available for older people and people with disability, including the Older Australians COVID-19 Support Line and the Coronavirus Disability Information Helpline at Federal level, and centralised web pages and newsletters for disability and aged care service providers issued by NSW Health. However, providing separate information pathways for each group, without tailored information being reflected in mainstream information sources, led to further duplication and confusion. Carers were also rarely addressed in targeted information and did not have their own centralised information sources.

In many cases, it was peak organisations and local, grassroots networks that developed and mobilised to coordinate localised support initiatives, including streamlined information and advice about accessing support services. These community and sector led responses were rapid and effective, however the lack of central and authoritative information did cause some confusion and anxiety. Drawing together and disseminating this information was also resource-intensive, especially for organisations with limited grant funding. The capacity of local organisations and networks to quickly respond to crises should continue to be valued and leveraged, however flexibility in existing grants, and new one-off grants, should continue to be made available to allow these local responses to be sustainable.

39. Australian Institute of Health and Welfare (2022), *People with disability in Australia 2022*, catalogue no. DIS 72, AIHW: Canberra; *Carers NSW (2022) Coronavirus (COVID-19) and carers: Carers NSW Position Statement*, 13 January 2022.
Carers NSW (2020a), *COVID-19 Literature Review: COVID-19 and carers*, Carers NSW: North Sydney.
Hofstaetter, L., Judd-Lam, S. and Cherrington, G. (2022), 'Informal care in Australia during the COVID-19 Pandemic', *International Journal of Care and Caring, vol.6*, issue 1-2, pp.253-259.
40. Physical Disability Council of NSW (2022).

Inclusive messaging

The absence of disability and carer-specific messaging in mainstream information sources,[41] combined with ableist and ageist public discourse and media commentary, gave many older people, people with disability and carers the impression that communities and governments did not care about protecting those with pre-existing conditions and at higher risk of poorer health and social outcomes, especially when restrictions were largely relaxed in early 2022.[42]

Misuse of the term 'carer' was also widespread in government and media messaging throughout the pandemic, where health professionals and support workers in aged care and disability care settings were referred to as 'carers', causing confusion and frustration among carers.

> ***"Every day they report numbers, and they say, 'That person had an underlying medical condition'. That doesn't make it OK that they died."***
>
> **- Physical Disability Council of NSW submission**

Proposed actions

2.1 Centralise and simplify official information sources and channels, with regard for consistency with Federal communications wherever possible.

2.2 Seek feedback from older people, people with disability and carers, including those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, on key information sources and formats to identify the most effective and inclusive communication methods.

2.3 Establish a short-term targeted grants program that enables cohort-specific peak organisations to rapidly expand their capacity to advise on, create and distribute targeted information during crisis periods.

2.4 Embed accessibility and inclusive language requirements into all public health communications frameworks.

2.5 Ensure mainstream public health helpline staff are able to provide accessible and cohort-specific information, rather than create separate information channels.

2.6 Consistently include key care service information (i.e. My Aged Care, NDIS and Carer Gateway contacts) alongside public health and mental health referral information in mainstream public health information.

2.7 Continue to provide and support community outreach initiatives to ensure at risk and hard to reach communities are aware of the services available to them.

41. Carers NSW (2020a); Hofstaetter et al (2022).
42. Physical Disability Council of NSW (2022); Yates et al (2020).

3 Access to services and support

Older people, people with disability and carers in NSW consistently reported challenges accessing informal support networks and formal services throughout the pandemic, both as a result of direct impacts of the virus on workforce supply and transmission risk, and restrictions put in place by governments and service providers to prevent transmission.

While limiting contact with COVID-positive or at-risk individuals is an important infection control measure, service interruptions and separation from loved ones had significant implications for the health and wellbeing of older people, people with disability and carers. A more stepped, inclusive approach to the communication and implementation of public health measures, and more equitable and timely access to PPE, Rapid Antigen Testing and vaccination could have reduced some of these impacts.

Contact with family members, friends and carers

Analysis of the aged care Royal Commission findings, as well as peak body publications regarding residential aged care facilities, indicated that many older people received inadequate opportunities to receive visitors during lockdown. Consequences of this ongoing lack of contact includes:

- Reduced emotional, social and practical care and support (such as mental stimulation, exercise, and assistance with feeding or showering)[43]
- Increased depression, anxiety and confusion, as well as isolation and heightened risk of suicide among residents[44]
- An absence of informal monitoring of the quality of care received by residents[44]
- Distress experienced by residents and their family members due to separation and inability to maintain contact.[46]

Residential care settings in both the aged care and disability sectors were subject to strict access requirements at various points in the pandemic, both in response to Federal-level service delivery protocols and NSW Government public health orders. These measures varied at the local level subject to risk level, provider policy and available staffing, but generally restricted the number of visitors to one nominated person or excluded visitors completely, other than in end-of life circumstances.[47] While these measures were deemed essential to reduce the impact of COVID-19 outbreaks in residential care facilities, the critical role of visitors in maintaining the overall health and wellbeing of people living in residential care settings became increasingly evident over the course of the pandemic.[48]

43. Hofstaetter et al (2022).; Carers NSW (2022); Royal Commission into Aged Care Quality and Safety (2020); Carers NSW (2020b).
44. Royal Commission into Aged Care Quality and Safety (2020).
45. Ibid.
46. Carers NSW (2020b).
47. Council on the Ageing (COTA) (2022), *Industry Code for Visiting in Aged Care Homes*, COTA Australia: Barton ACT.
48. Royal Commission into Aged Care Quality and Safety (2020), *Aged care and COVID-19: a special report*, pp.1-30; Yates et al (2020)

In response to this issue, the Council on the Ageing (COTA) introduced the Industry Code for Visitation in Aged Care Homes[49] and the Older Persons Advocacy Network (OPAN) offered advice and advocacy to older people and carers regarding visitation restrictions. While the Industry Code operates as a 'best practice' model and is not legislated or enforceable, explicit direction was given to aged care providers by the Department of Health and Aged Care to allow visitation when required for essential care.

The Industry Code was last updated in March 2022 and has received wide endorsement from consumer, carer, and aged care peak bodies. The subsequent 'Partnerships in Care' initiative by the Aged Care Quality and Safety Commission is a promising development that offers ongoing prioritisation of visitation to support residents' quality of life, within and beyond crisis periods.[50]

It is important to note, however, that the Industry Cost and Partnerships in Care initiative may be ineffective without adequate workforce resourcing and support, and without monitoring, incentivisation and enforcement.[51] It is also important to note that, while a considerable degree of attention was paid to visitation of residential aged care, considerably less planning and communication occurred regarding access to residential disability and mental health settings, and hospitals. This created complexity and distress for many people with disability and carers.

> ***"My nan's cognition declined a lot during COVID-19, especially when her community activities were suspended. Long wait times for in-home aged care services meant that she had to move to residential aged care earlier than planned to ensure her safety. Visitation to the nursing home was stopped due to COVID-19, which saw her cognition decline further. Staff are lovely and well-meaning but the level and quality of care isn't great (i.e. hearing aids never charged). We also got locked in the dementia ward for 15 minutes as we could not locate a single staff member to assist us to exit the locked ward."***
>
> **- 2022 National Carer Survey respondent**

49. Council on the Ageing (2022)
50. Aged Care Quality and Safety Commission (2022), *Partnerships in Care*, available online at: https://www.agedcarequality.gov.au/resources/partnerships-in-carep31 January 2023.
51. Hofstaetter et al (2022); Select Committee on COVID-19 (2020).; Select Committee on COVID-19 (2022).

Contact with health care professionals

Reports indicate that older people, people with disability and carers all had reduced contact with health care professionals during the pandemic, raising concerns for those with pre-existing and newly identified physical and mental health issues. The most common reasons for this included the closure of in-person services and redirection to delivery via telehealth[52] and the cancellation or reduction of in-home care support.[53] Underlying these measures was the increasing risk of infection, staff shortages and inadequate supply of PPE and Rapid Antigen Testing.[54] Telehealth was considered by many to be a convenient and accessible service innovation,[55] however, many people with disability have reported that it is difficult to access and does not provide an equivalent level of service.

> ***"Unable to attend gynaecologist appointments for my Mother due to COVID lockdowns. Had to find alternative Dr for monitoring of prolapse and order & wait for pessary device to be provided by local chemist. Oncology appointments were over the phone, delayed and postponed a few times during COVID. Traveling distances of over 100kms to see specialists."***
>
> **- 2022 National Carer Survey respondents**

> ***"Due to COVID there's been many appts cancelled and never rescheduled just ignored requiring new GP referrals to specialists...whilst aggressive rare cancer grew on my daughters neurofibroma... awaiting specialist appts."***
>
> **- Carer Survey 2022**

Firstly, with many older people and people with disability having limited digital literacy, the responsibility often fell to carers to enable the use of technology to access health care.[56] Additionally, in some cases carers had to replace or supplement specialised formal care services, such as facilitating the delivery of practical therapies through telehealth without adequate support and training.[57] This raised concerns for those receiving care, who without a carer present were potentially unable to access telehealth services, as well as the visual and hands-on care required for many physical therapies. Lack of prior training for carers providing practical therapies also raised concern over the quality of care being received by patients.[58]

Telehealth also presented communication issues for older people, people with disability and carers, with some patients experiencing barriers to building rapport with their health providers and hence feeling a reduced sense of support and belonging.[59] Finally, closure of in-person health services resulted in a large number of older people, people with disability and carers missing routine appointments and treatments that may result in serious health consequences in the short and long term.[60]

52. Ibid.; Carers NSW (2020a).; Children and Young People with Disability Australia (2022).; Kavanagh et al (2020b).
53. Carers NSW (2020b).; Yates et al (2020).
54. Children and Young People with Disability Australia (2022).
55. Ibid.
56. Carers NSW (2020b).
57. Hofstaetter et al (2022).
58. Ibid.
59. Children and Young People with Disability Australia (2022); Council on the Ageing (2022).
60. Yates et al (2020).; Council on the Ageing (2022).

Navigating systems and services

Consultation with carers identified that service systems designed to assist older people, people with disability and carers were not easy to use during the pandemic, and this resulted in feelings of isolation and inability to access timely support. Government and community-based COVID-19 response systems and services, such as modified guidelines and service types delivered through My Aged Care and Centrelink, as well as COVID-19 specific services such as priority vaccination, priority shopping, and priority rapid antigen test (RAT) distribution schemes, were difficult to navigate.[61] Reasons for this difficulty included limited digital literacy,[62] restrictive eligibility and documentation requirements,[63] and long waiting periods.[64] The most common consequences of this difficulty included inability to access income support payments;[65] inability to access essential items such as groceries, PPE and RATs;[66] and inability to access vaccinations or other health services.[67]

The challenges of COVID-19 for frontline service delivery led the NSW Government to invest in a number of new and expanded funding opportunities to support the sector, for example through the Combatting Social Isolation for Seniors during COVID-19 Grants Program, the Social Sector Transformation Fund and increased funding to homelessness and domestic violence services. Additionally, the NSW and Australian governments responded quickly to sector feedback by adapting service delivery guidelines and reporting requirements to allow grant funded community service providers to meet emerging needs. Providers were given flexibility to, for example, temporarily adapt their eligibility criteria, expenditure categories, individual funding caps and service offerings to address arising issues at the local level. This agility was welcomed by the sector, with ongoing flexibility to adapt to local challenges recommended.

> ***"Lack of access to systems and services and lack of inclusive practise, isolates carers as well as the person they care for."***
>
> ***"Over the COVID period, I do feel like there was little support and help for my elderly father. He could not understand many of the changes and telehealth was very difficult for him, GP reception staff were often rude and there was no patience or empathy for elderly people who were not tech savvy or had a disability. My fight for my father has been the only thing that has helped us getting the right help."***
>
> **- 2022 National Carer Survey respondents**

61. Carers NSW (2020b).
62. Ibid.
63. Ibid.
64. Ibid.
65. Ibid.; Carers NSW (2020a).
66. Carers NSW (2020b).
67. Children and Young People with Disability Australia (2022).

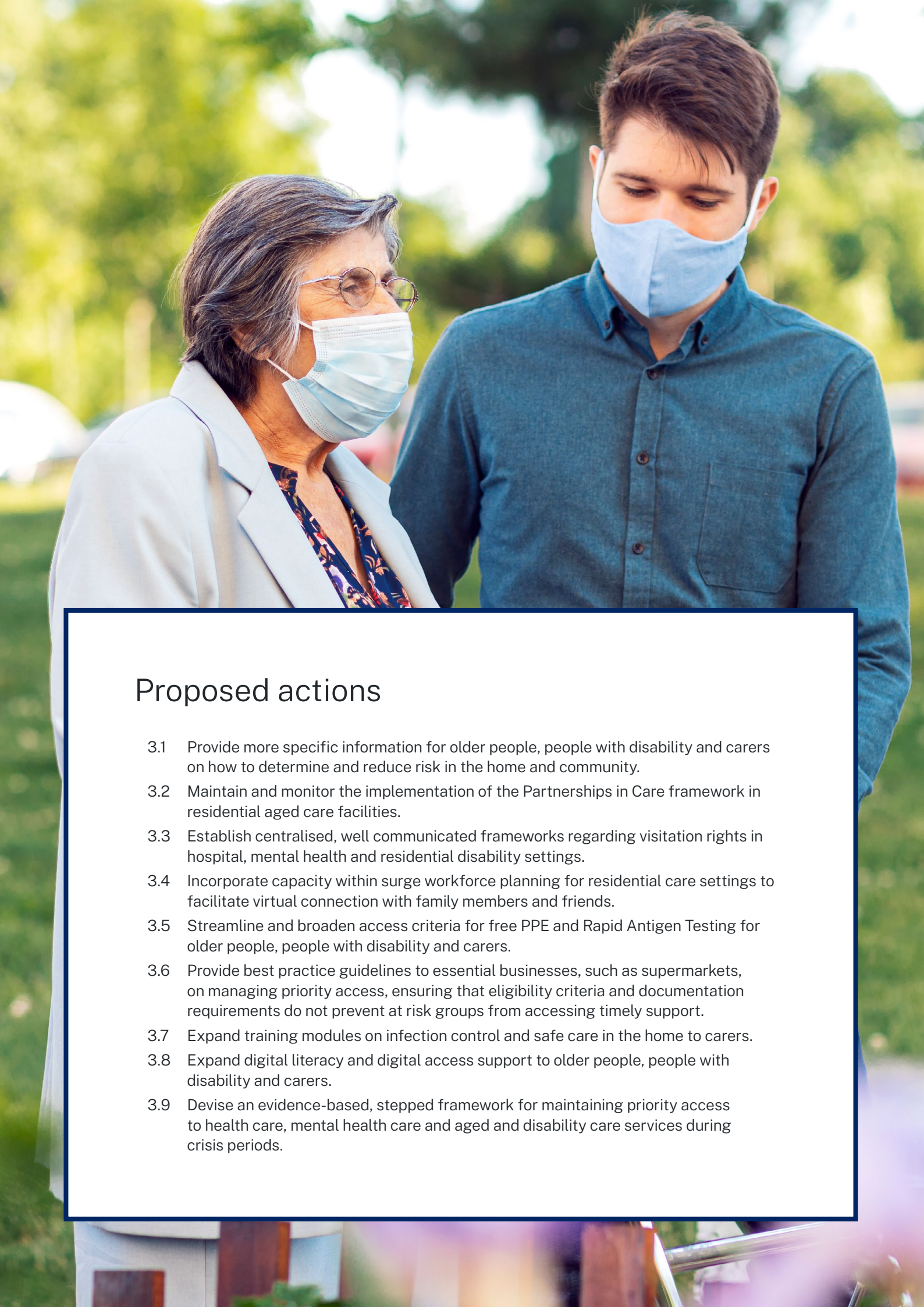
Breaks from caring responsibilities

Reduced access to informal support networks (e.g. relatives and neighbours) and formal services (e.g. from the NDIS, My Aged Care or Carer Gateway) that would usually enable breaks from the caring role was a very common theme for carers, leading to high levels of stress and exhaustion.[68] Due to gathering and movement restrictions, carers were often unable to take time away from their caring responsibilities or focus on their own health and wellbeing.[69] Additionally, respite care centres closed or offered limited places due to the risk of infection.[70] This also meant that many older people and people with disability missed out on their usual community engagement and recreational activities.[71]

A more nuanced, evidence-based approach to implementing service closures coupled with improved access to PPE and Rapid Antigen Testing, and clearer information for the community on risks and infection control, could have reduced the isolation experienced by older people, people with disability and carers.

> ***"Have not yet received respite due to COVID and have been in receipt of level three package since about November 2021. Services are sometimes late or not accessed due to staff shortages."***
>
> **- 2022 National Carer Survey respondent**

68. Carers NSW (2020b).
69. Carers NSW (2020b).
70. Ibid.; Yates et al (2020).
71. Yates et al (2020).



Proposed actions

3.1 Provide more specific information for older people, people with disability and carers on how to determine and reduce risk in the home and community.

3.2 Maintain and monitor the implementation of the Partnerships in Care framework in residential aged care facilities.

3.3 Establish centralised, well communicated frameworks regarding visitation rights in hospital, mental health and residential disability settings.

3.4 Incorporate capacity within surge workforce planning for residential care settings to facilitate virtual connection with family members and friends.

3.5 Streamline and broaden access criteria for free PPE and Rapid Antigen Testing for older people, people with disability and carers.

3.6 Provide best practice guidelines to essential businesses, such as supermarkets, on managing priority access, ensuring that eligibility criteria and documentation requirements do not prevent at risk groups from accessing timely support.

3.7 Expand training modules on infection control and safe care in the home to carers.

3.8 Expand digital literacy and digital access support to older people, people with disability and carers.

3.9 Devise an evidence-based, stepped framework for maintaining priority access to health care, mental health care and aged and disability care services during crisis periods.

4 Financial pressure

Financial pressure increased during the pandemic due to difficulties maintaining employment and the rising cost of living, causing many people to struggle to afford basic necessities. Many older people, people with disability and carers in particular experienced financial pressure during the pandemic. As a result of increased caring responsibilities, and due to increased risk of infection or severe illness, many older people, people with a disability, and carers lost employment and in-turn a stable income.[72] Price increases and supply shortages for essential goods and services only increased financial pressure for these groups.

> ***"Extremely difficult mentally and financially, especially since COVID-19, I stepped out of my casual position at Woolworths (25 years) as I feared mum would die if she contracted this"***
>
> **- 2020 National Carer Survey respondent**

Despite being among the first to lose work and experience higher living costs as a result of lockdown, the Age Pension, Disability Support Pension, and Carer Payment were ineligible for the additional Coronavirus Supplement payment.[73] This was commonly perceived as a lack of recognition of the financial insecurity experienced by older people, people with disability, and carers.[74]

Of those who retained work during the pandemic, many were unable to access appropriate leave (personal and/or carers) entitlements through their employer.[75] Others were unable to work from home or experienced a reduction in hours of employment.[76]

Increased living expenses during the pandemic costs reflected the limited availability of essential goods and services due to supply chain disruption and panic buying.[77] Housing costs (e.g. rent), utility bills, and incidental expenses (such as smart devices to use for telehealth appointments, work or studying) also increased with more time spent at home.[78] The loss of income and inability to access income support, coupled with the rising cost of living, left some older people, people with disability and carers unable to afford essential items such as groceries and medication.[79]

Proposed actions

4.1 Encourage workplaces to embed flexibility to allow older people, people with disability and carers to adjust their work location and hours where possible.

4.2 Prioritise inclusion of older people, people with disability and carers in the distribution of essential goods and services.

4.3 Expand financial security initiatives, including adjustments to income support, to include people on the Age Pension, Disability Support Pension and Carer Payment.

72. Carers NSW (2020a).
Carers NSW (2020b).
73. Select Committee on COVID-19 (2020).
74. Carers NSW (2020a).
75. Carers NSW (2020b).; Carers NSW (2022).
76. Carers NSW (2022).
77. Australian Institute of Health and Welfare (2022); Carers NSW (2022).
78. Carers NSW (2020b).
Hofstaetter et al (2022).
79. Australian Institute of Health and Welfare (2022).; Carers NSW (2022).

5 Mental and physical health

Mental and physical health declined during the pandemic due to a number of factors, including social isolation, fear of illness and discrimination, constantly changing rules and regulations and a lack of access to regular self-care activities, such as exercise and recreation, supporting good health.

Social isolation and mental health

Research indicates that the social isolation resulting from gathering and movement restrictions increased the overall risk of depression, anxiety and loneliness.[80] However, for those with digital literacy, access to digital devices and adequate internet connection, social inclusion was maintained and even increased through the increased uptake and functionality of online communication methods.[81] With the lifting of restrictions, reduced availability of online alternatives as social activities and service delivery revert to predominantly face-to-face may mean that those who found new ability to engage during the pandemic, are now facing increased social isolation.[82]

> ***"I think for me it was a bit of a mix because in person spaces before COVID-19 was a huge thing and masks weren't a thing, I could generally manage with lip reading. But now events are kind of like in person with masks or over Zoom without captioning and both of those are super inaccessible to me."***
>
> **– CYDA response**

> ***"My Mum experienced dementia deterioration, hygiene issues escalating due to room isolation, increased depression & anxiety due to "neglect" & staff shortages, which is why I asked to help & at times called in 2 or 3 times per week as her dementia behaviours escalated."***
>
> **- 2022 National Carer Survey respondent**

80. Yates et al (2020).
81. Children and Young People with Disability Australia (2022)
82. Ibid.

Fear of infection and hospitalisation

Consultation with older people, people with disability and carers has indicated that these groups feared the implications of contracting COVID-19, given their increased risk of adverse outcomes and reliance on informal and formal supports. One of the main contributors to this fear of infection was an inadequate level of contingency planning in the case that the primary carer became ill and was unable to care for their older person or person with disability.[83]

> *"If my son got COVID-19 and was hospitalised, we [carer and husband] could not support him in hospital... health clinicians could not communicate due to [my] son's speech impairment and he would be traumatised"*
>
> **- Carer of adult with disability**

Another genuine concern was for the treatment of older people and people with disability if they were to become ill.[84] Messaging from the health care system and concerns about ongoing ableist and ageist bias within society made some older people and people with disability fear that their conditions could impact their access to critical health care, especially if they were to become unwell and deemed unworthy of treatment.[85]

A lack of recognition of the distinct experiences of older people and people with disability increased anxiety among these groups that they were being overlooked in government and community responses.[86] For example, the 'let it rip' approach by the NSW Government to lifting restrictions during the Omicron wave of the virus in 2022 exacerbated psychological distress for older people, people with disability and carers because it suggested that their lives were somehow less valuable.[87] Furthermore, insufficient recognition of the level of support being provided by carers left many carers feeling invisible and unsupported.[88]

> *"We [carers] are often invisible. Dealing with government services can be appallingly difficult. What as a society do we actually want people to do when they're vulnerable, sick or elderly? It's often felt through the last two and a half years of COVID that we are considered collateral damage and entirely expendable"*
>
> **- 2022 National Carer Survey respondent**

83. Carers NSW (2020a).
84. Carers NSW (2020b); Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2022).
85. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020); Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2022).
86. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020).
87. Children and Young People with Disability Australia (2022).
88. Carers NSW (2020a); Hofstaetter et al (2022).

Constantly changing rules and regulations

Ever-changing rules and regulations, and varying compliance by others in the community, were a source of distress for at risk groups, inhibiting their ability to access necessary services and reducing their confidence in their decision making.[89] Additionally, the sheer volume of information resulted in a sense of information overload for many.[90]

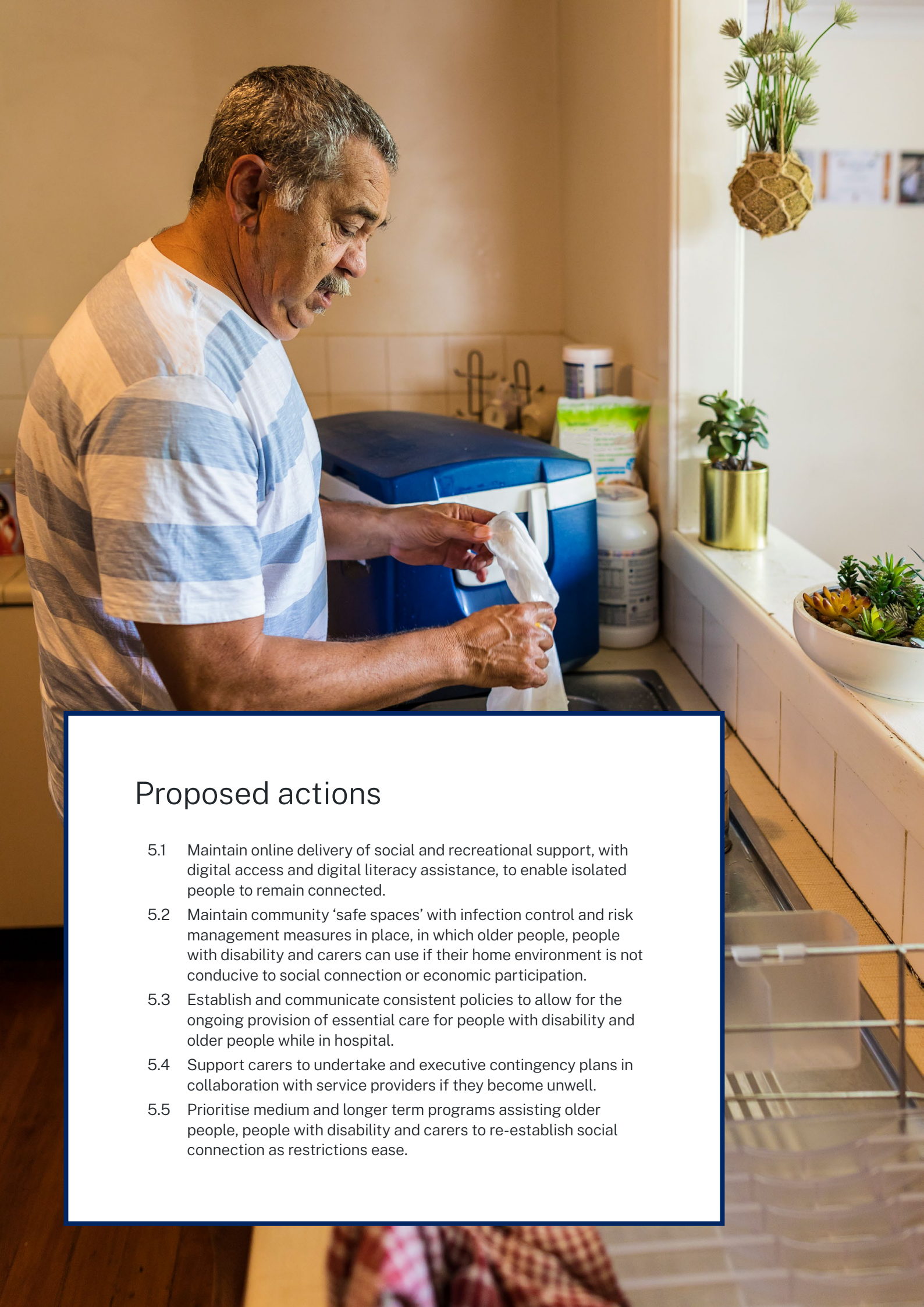
Disrupted routines and limited personal space

Many reports indicated that stress resulted from disrupted routines and limited space within the home leading to an increase in challenging behaviours, confusion and depression among those with cognitive impairments, and in some cases an inability to sustain employment or education on top of managing a health condition or caring responsibilities.

Working from home and home schooling as well as the suspension of health services and recreational activities has also been challenging for many older people, people with disability, and their carers. A reduction in routine activities including outings and visitation has not only increased rates of depression, but also increased the risk of loss of cognitive function in some older people due to a lack of mental stimulation.

> ***"I feel emotional and exhausted trying to explain to my 44-year-old son that he is not able to keep his usual routine. Daily outings that [he] enjoys are no longer possible, and it is challenging to be at home with [him] and my husband all of the time"***
>
> **- Carer of an adult with disability**

89. Carers NSW (2020b).
90. Ibid.



Proposed actions

5.1 Maintain online delivery of social and recreational support, with digital access and digital literacy assistance, to enable isolated people to remain connected.

5.2 Maintain community ‘safe spaces’ with infection control and risk management measures in place, in which older people, people with disability and carers can use if their home environment is not conducive to social connection or economic participation.

5.3 Establish and communicate consistent policies to allow for the ongoing provision of essential care for people with disability and older people while in hospital.

5.4 Support carers to undertake and executive contingency plans in collaboration with service providers if they become unwell.

5.5 Prioritise medium and longer term programs assisting older people, people with disability and carers to re-establish social connection as restrictions ease.

Conclusion

This paper has examined the ways in which COVID-19 has impacted older people, people with disability and carers in NSW since 2020. A range of common challenges were identified in relation to these groups that resulted from the virus itself and from the community and government response. It proposes a range of actions for how the NSW and Australian governments can improve information and support for older people, people with disability and carers as the pandemic continues to evolve, and in future public health crises. Overall, 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 among these target groups.

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The following is a list of sources of which some are referenced directly within the body of the report but all have broadly informed the information presented in this report.

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