



What carers need

Carers NSW Pre-Budget Submission 2023-24

ABOUT CARERS NSW

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.

www.carersnsw.org.au

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

ABOUT CARERS

A carer is any individual who provides unpaid 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.

Across NSW, there are approximately 854,300 carers,¹ and to replace the care they provide the NSW Government would have to spend more than \$25 billion each year.² Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

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November 2022

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¹ Australian Bureau of Statistics (ABS) (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, New South Wales Tables, Canberra.

² Carers NSW estimate based on Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*, Carers Australia.

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INTRODUCTION

Following an extended period of constant disruption from natural disasters and the COVID-19 pandemic, 2022 has continued to bring a number of challenges to the people of New South Wales (NSW). Carers have been among the many NSW residents who continue to be adversely affected by rolling crises, and are experiencing significant associated physical, emotional and financial impacts. Ahead of the next NSW State Budget, this Pre-Budget Submission reflects on key findings from Carers NSW research and consultation with carers and service providers to identify areas requiring additional investment from the NSW Government. It also recognises the Government's considerable existing and new investment in carer recognition and support through the prior and current NSW Carers Strategies.

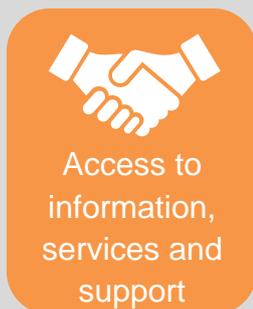
As we celebrate the growing reach of the dedicated Federal service system for carers – Carer Gateway – and the completion of the *NSW Carers Strategy: Action Plan 2020-22*, Carers NSW seeks to draw on learnings from the many challenges and changes of recent financial years to inform Government expenditure into 2023-24.

As communities enter 'COVID normal', many carers continue to experience ongoing and long-lasting impacts of COVID-19. For carers adversely affected by natural disasters, these impacts have only been amplified. While financial and emotional pressure on carers grows and intensifies, the focus on carers and their needs continues to wane across a number of service systems, and increasingly carers' needs are not able to be met through existing services and supports. As we enter a period of reconnecting and rebuilding, it is vital that the NSW Government invest in ongoing and additional support for carers to overcome the greater impacts and additional challenges they face.

By 2023-24, the findings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability will be released, current aged care reforms stemming from the Royal Commission into Aged Care Quality and Safety will be further progressed and a clear path forward for aged care and disability services and support will be emerging, with significant implications for NSW residents using these service systems. These changes will provide welcome opportunities to improve support for carers, but may also result in continued upheaval and confusion for many carers and the people they care for, who have already been navigating major system change and complexity for a number of years.

In light of the many challenges and changes of the present State Budget period, this Pre-Budget Submission highlights four key areas for ongoing and additional NSW Government investment that align with the *NSW Carers Strategy: Caring in NSW 2020-2030* - carer recognition, respect and empowerment, access to information, services and support, financial wellbeing and economic opportunities and better health and wellbeing. Engaging carers at all stages of service planning and delivery and meeting the unmet needs of carers are key priorities of the NSW Carers Charter and NSW Carers Strategy. This Pre-Budget Submission makes a range of practical recommendations for how these important principles can be progressed in the 2023-24 Budget Period.

Carers need...



SUMMARY OF RECOMMENDATIONS

1. Carers need increased recognition, respect and empowerment

- 1.1 Adequately resource the **second Action Plan for the NSW Carers Strategy** to enable effective implementation (see pages 9-11)
- 1.2 Explore additional opportunities to **invest in sustainable carer-focused projects** (see pages 9-11).
- 1.3 Resource the implementation of the updated **Being a Carer, Being a Student and Being a Kid resource** in schools (see pages 11-12)
- 1.4 Invest in the development and implementation of a **carer-friendly schools recognition/accreditation** program (see pages 11-12)
- 1.5 Progress the review and improvement of the **NSW Companion Card application process** (see pages 13-14)
- 1.6 Progress ongoing work to improve **carer identification in health care and customer service settings** (see pages 13-14)
- 1.7 Continue to explore opportunities within emerging digital identity capabilities to improve carer recognition, such as through the **implementation of a NSW Carer Card** (see pages 13-14)
- 1.8 Allocate and/or announce the service provider for the **carers and families systemic advocacy stream** under the Disability Advocacy Futures Program (see page 14)
- 1.9 Continue to invest in carer-inclusive initiatives focusing on **improving outcomes in regional and rural NSW** (see pages 14-15)
- 1.10 Ensure that carers are identified as a **priority or target group within all rural and regional initiatives** (see pages 14-15)

2. Carers need better access to information, services and supports

- 2.1 Prioritise the **implementation of a Supported Decision Making model** within NSW legislation in consultation with vulnerable groups, the sector and experts (see pages 15-16)
- 2.2 Invest in **evidence-based pilot projects** that aim to provide education, resources and support that enable Supported Decision Making approaches (see pages 15-16)
- 2.3 Continue to resource the **development and rollout of evidence-based abuse prevention resources and training** to carers, service providers and the wider community (see pages 16-17)
- 2.4 Continue and expand investment in **supportive, evidence-based approaches to family conflict resolution** such as elder mediation services (see pages 16-17)
- 2.5 Continue to **resource the review of technology assisted voting** and invest in the development of new technology assisted voting mechanisms (see pages 17-18)
- 2.6 Consider **extending eligibility for technology assisted voting** to additional groups who may benefit from this such as carers (see pages 17-18)
- 2.7 Increase investment in programs such as the AIDER program that provide **practical and financial support with disaster preparedness** (see pages 19-20)
- 2.8 Invest in **small household preparedness grants** to fund household risk reduction modification and maintenance (see pages 19-20)
- 2.9 Explore opportunities to **embed requirements for inclusive disaster preparedness** within existing mechanisms such as Local Emergency Management Plans (see pages 19-20)
- 2.10 Develop and strengthen relationships with representatives of Federally funded care service systems to enable **improved coordination following natural disasters** (see pages 20-21)
- 2.11 Embed requirements for the **presence of care sector agencies in affected regions** following natural disasters in emergency response planning (see pages 20-21)

- 2.12 Invest in increased and ongoing **trauma-informed mental health supports** in disaster-affected regions (*see pages 20-21*)
- 2.13 Invest in **streamlining application processes for accessing disaster supports** through Service NSW (*see pages 21-23*)
- 2.14 **Review the 'Request for assistance form'** in consultation with carers and the people they care for to ensure that it adequately reflects the types of assistance they may need (*see pages 21-23*)
- 2.15 Invest in a **Seniors Concierge Service** within Service NSW to assist with navigation of state and federal ageing related services and supports (*see pages 23-24*)
- 2.16 Invest in state-based support and resources aimed at **improving the health and wellbeing of workers** in the NFP and social support sector (*see page 24*)

3. Carers have improved financial wellbeing and economic opportunities

- 3.1 **Expand the Dine & Discover NSW voucher scheme** to include targeted supports for carers, including vouchers for essential items such as grocery and fresh produce, and some products available through pharmacies (*see pages 25-26*)
- 3.2 Recognise carers as a vulnerable group and as partners in care, and **expand eligibility for public transport concession subsidies**, including Opal Concession Card, to include carers not currently eligible (*see pages 25-26*)
- 3.3 **Enable carers to access pre-existing energy rebates**—including gas, water, and electricity—which are currently restricted to concession card holders, families and seniors (*see pages 25-26*)
- 3.4 Continue to support a **focus on carers' financial wellbeing in the second Action Plan** for the NSW Carers Strategy (*see pages 26-27*)
- 3.5 **Centralise and expand on employment supports for carers** through the investment in the development and implementation of a Carers + Employment Hub (*see pages 27-28*)
- 3.6 **Extend and expand the Return to Work Program**, with a continued prioritisation of carers seeking to return to work (*see pages 27-28*)
- 3.7 **Improve integration of the Return to Work Program** with existing carer-focused employment support programs (*see pages 27-28*)
- 3.8 Continue to invest in **campaigns promoting the benefits of the COVID-19 vaccinations**, including boosters, and ensure vaccinations are free and accessible (*see pages 28-29*)
- 3.9 Extend and expand schemes that provide **free or subsidised COVID-19 Personal Protective Equipment and Rapid Antigen Tests** at key local services, such as pharmacies, medical centres and Service NSW Service Centres (*see pages 28-29*)
- 3.10 **Maintain infection control measures** within high risk settings (*see pages 28-29*)
- 3.11 **Prioritise new social housing development allocations** for people with existing vulnerabilities, including people with disabilities or who are frail and their carers (*see page 30*)
- 3.12 Investigate and analyse the social housing needs of carers to ensure the development of **appropriately sized social housing dwellings that cater for multigenerational households** (*see page 30*)
- 3.13 Improve and increase accessible housing availability by **signing onto the accessibility requirements of the National Construction Code** (*see pages 30-31*)
- 3.14 Source **additional temporary housing with greater accessibility features** for regions impacted by natural disasters (*see pages 31-33*)
- 3.15 **Prioritise carers and the people they care for** in temporary housing allocations, with a focus on accessibility and support service needs (*see pages 31-33*)

4. Carers need better health and wellbeing

- 4.1 **Extend eligibility for transport schemes and rebates** to carers to enable them to tend to their own health and wellbeing activities (*see pages 34-35*)
- 4.2 Invest in transport solutions that support carers to **access health and medical appointments** (*see pages 34-35*)
- 4.3 Consider opportunities for **replacement care within health settings** that enable carers to meet their own health needs (*see pages 33-35*)
- 4.4 Invest in a state-wide carer-focused **digital literacy and digital access** program (*see pages 36-37*)
- 4.5 Continue to explore opportunities to **fund or subsidise digital devices** for financially disadvantaged groups such as carers to support social connection online (*see pages 36-37*)
- 4.6 Invest in additional education and resources for carers to **reduce the risk of financial losses due to online scams or cybersecurity risks** (*see pages 36-37*)
- 4.7 Invest in a **small grants program for carer support groups** to meet ongoing costs of facilitating carer support groups in NSW (*see pages 37-38*)
- 4.8 Invest in short term care and support packages that **meet the care needs of carers and the people they care for with long COVID** (*see pages 38-39*)
- 4.9 Develop and implement a long-term, carer-inclusive strategy for **addressing the care and support needs of carers and people receiving care with long COVID** (*see pages 38-39*)

1. Carers need increased recognition, respect and empowerment

2022 marks the end of the first two-year Action Plan of the *NSW Carers Strategy: Caring in NSW 2020-2030* (the Strategy). Carers NSW commends the NSW Government's commitment to carer recognition and support, and to more concrete, shorter term Action Plans that allow for specific projects and cohorts to be prioritised as the Strategy is implemented over time.

Carers NSW has appreciated the opportunity to lead and support a number of projects under the 2020-22 Action Plan, including ongoing work in partnership with the NSW Department of Communities and Justice (DCJ) in the areas of carer rights education, carers' financial literacy, carer-friendly workplaces and carer awareness. We are looking forward to continue progressing and expanding these activities into the next Action Plan.

Carers NSW also commends DCJ's ongoing commitment to carer recognition through funding the Carers NSW 2022 National Carer Survey, the Carer Knowledge Exchange, the 2022 Carers Week grants and the Carers NSW 2022 Conference, along with other health and wellbeing and carer awareness focused initiatives, as well as conducting its own regular communications and targeted awareness campaigns to highlight carers.

What carers need for increased recognition in NSW

DCJ's ongoing work with Carers NSW and other key stakeholders in implementing the Strategy and promoting the *NSW Carers (Recognition) Act 2010* and *NSW Carers Charter* reflects the NSW Government's genuine commitment to collaboratively improving outcomes for carers. However, challenges continue for many carers in the areas of recognition and inclusion, providing additional opportunities for NSW Government departments and agencies to work innovatively and engage more with carers and the people they care for.

The Carers NSW 2022 National Carer Survey³ identified a strong relationship between recognition and wellbeing, with higher recognition associated with better wellbeing, and vice versa (see Figure 1). Despite the NSW Government's ongoing commitment to carer recognition, the Survey also found that carers in NSW continue to report low levels of recognition across a range of domains.⁴ Only 2 in 5 NSW respondents felt that their caring role was recognised by service providers, just over 1 in 4 felt recognised by the community, and just under 1 in 7 reported that they felt recognised by governments (see Figure 2).

"Caring for someone during the COVID-19 pandemic was increasingly difficult. The almost instant removal of established routines and arrangements, combined with food shortages and ever-changing restrictions severely increased the workload of carers. It is a shame that they have not been acknowledged for their valuable contribution during this time."

- Carers NSW 2022 National Carer Survey respondent

³ Carers NSW (2022a) *2022 National Carer Survey, unpublished data.*

⁴ Carers NSW (2022a).

Figure 1. Relationship between carer recognition and carer wellbeing (PWI)

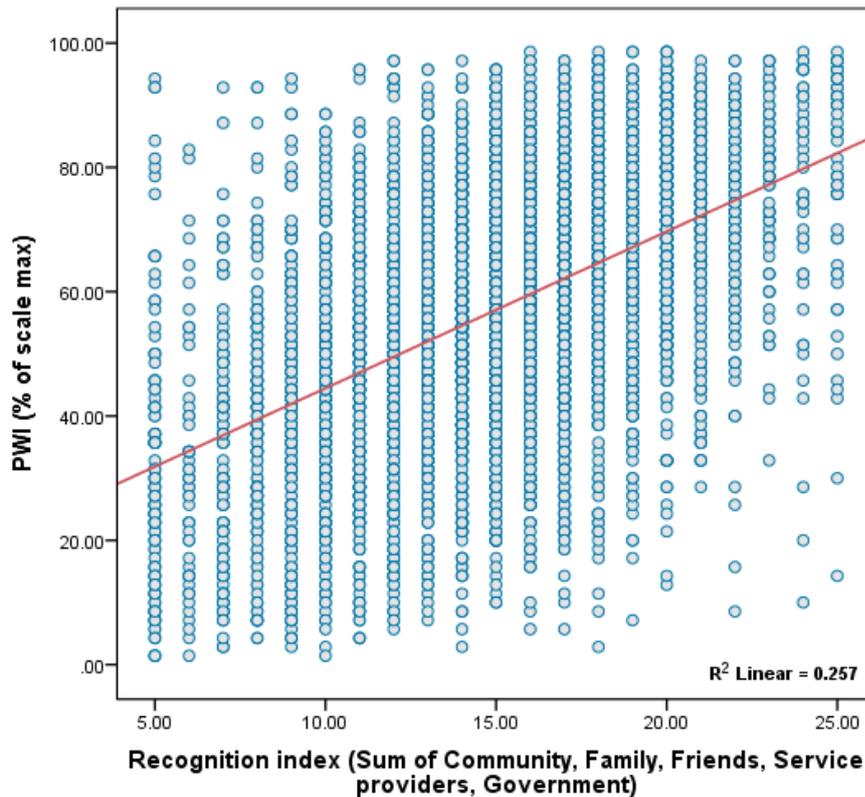
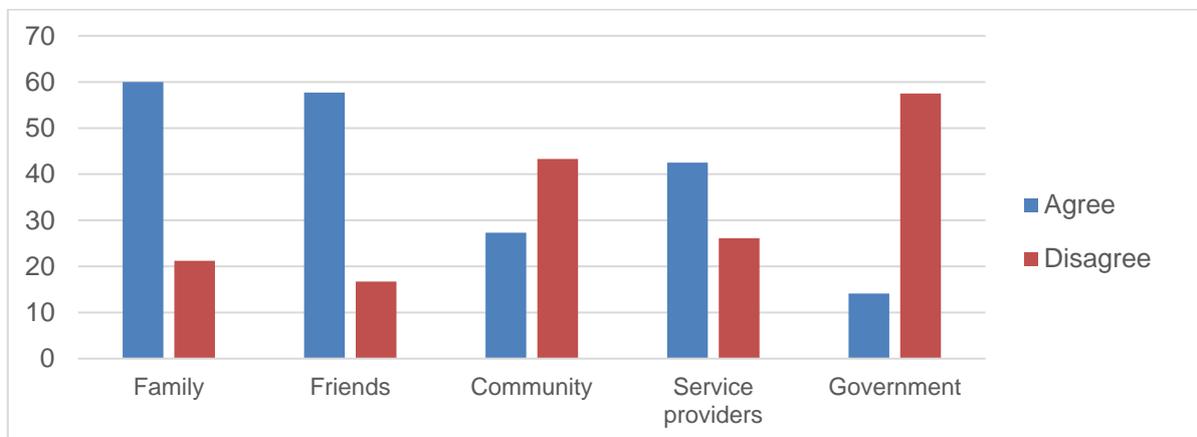


Figure 2. Carer recognition in NSW: “I feel that my caring role is recognised and valued by...”



While self-reported levels of recognition in most domains remain low, positively, in 2022 carers in NSW reported higher levels of recognition by family, friends, service providers and the community than in the 2020 National Carer Survey.⁵ However, compared to 2020, carers in NSW reported lower levels of recognition by government in the 2022 National Carer Survey. While 'government' in this context could refer to any level of government, findings from the Survey regarding services primarily delivered by the NSW Government (public health and mental health services) indicate that carers are not often asked about their own needs, or provided with adequate support to meet their needs.⁶ Accordingly, Carers

⁵ Carers NSW (2020) *2020 National Carer Survey, unpublished data.*

⁶ Carers NSW (2022a).

NSW encourages the NSW Government to continue advancing carer recognition in NSW, in line with Priority area 2 of the Strategy: ‘Carers will be recognised, respected and empowered’.

Phase one of the Carers NSW Carer Rights Education project,⁷ commenced in 2017 and included in the first Action Plan of the current Strategy, has supported carers to better understand their protected rights under a variety of sector and industry specific legislation and mechanisms, as well as the redress pathways available to them. The *Know Your Rights* fact sheets and videos co-developed under this project in partnership with DCJ and the complaints sector remain in high demand from carers and appear to have supported many more to access complaints pathways. While Carers NSW is pleased that the Carer Rights Education project is intended to continue throughout the life of the Strategy, there remains a need for the actual rights and protections in place for carers to be strengthened.

“I wish the role of carer was valued by society and the government. I'd like to feel proud of what I do. I also wish that our family did not have to suffer financial difficulties because I am unable to work.”

- Carers NSW 2022 National Carer Survey respondent

The second Strategy Action Plan, currently in development, will provide ongoing and additional opportunities for different parts of the NSW Government to continue championing carer recognition. Ensuring that Action Plan projects and outcomes are adequately resourced will be essential for continued success of the Strategy. Furthermore, following the cessation of a number of successful Carer Investment Program (CIP) project grants in 2021, Carers NSW encourages the NSW Government to continue to explore opportunities to invest in evidence-based, sustainable carer-focused projects to support the delivery of the Strategy.

Recommendations

- 1.1 Adequately resource the second Action Plan for the NSW Carers Strategy to enable effective implementation
- 1.2 Explore additional opportunities to invest in sustainable carer-focused projects

What carers need for increased recognition and support within schools

In NSW there are an estimated 83,700 young carers up to the age of 25 years,⁸ however this is likely an underestimate of the young carer population size, as young carers often do not identify as young carers, or disclose their caring responsibilities. With lower levels of identification and recognition in the community, young carers also experience additional barriers to accessing timely and appropriate support, which can adversely affect their school attendance and attainment.⁹

There are many reasons that young carers may not identify or be identified as carers. Some may view the support that they provide as an intrinsic part of their role as a sibling, daughter/son, parent, relative, spouse or friend. Others do not identify as young carers because they, or the people around them, do

⁷ Carers NSW (2022b) *Rights and Complaints, Carer rights*, available online at: <https://www.carersnsw.org.au/services-and-support/advice-for-carers/rights-and-complaints#carer-rights>, viewed 04 November 2022.

⁸ ABS (2019).

⁹ Hamilton, M. and Redmond, G. (2020) ‘Are Young Carers Less Engaged in School than Non-Carers? Evidence from a Representative Australian Study’, *Child Indicators Research*, 13(1), 33-49; Warren, D. and Edwards, B. (2017) ‘Young carers’, *Longitudinal Study of Australian Children Annual Statistical Report 2016*, Australian Institute of Family Studies, Canberra.

not know what a young carer is, or because they are afraid of the implications of disclosing their family situation, which could lead to stigma or bullying, or raise questions around child protection.¹⁰

Despite existing initiatives aimed at increasing recognition and support for young carers, many continue to report low levels of recognition of their caring role. Interestingly, the Carers NSW 2022 National Carer Survey found that young carers nationally¹¹ reported higher levels of recognition by their family members than other carers. However, they reported lower levels of recognition than other carers in all other domains.

School settings provide an important opportunity for young carers to be identified and linked in with supports. However, ongoing low levels of carer awareness may see students' caring roles overlooked or not formally identified, limiting access to available support. The Carers NSW Young Carer Program currently offers free Young Carer Awareness Training (YCAT)¹² to improve understanding and identification of carers within school settings. While this training is well received and effective in raising awareness of young carers, gaining access to schools and securing ongoing engagement and commitment to young carer identification and support by schools can be a challenge, which has only been further exacerbated by the considerable demands on schools to manage the COVID-19 pandemic.

To increase and progress carer recognition within schools, Carers NSW believes that the NSW Government should invest in additional practical support for schools that expands on or complements YCAT. This could include assisting schools to implement the NSW Department of Education resource, *Being a Carer, Being a Student and Being a Kid* and to review and monitor their policies and practices, improving identification and support for students with caring responsibilities. A supported stepped accreditation model, similar to that delivered through the Carers NSW Carers + Employers program,¹³ may be one possible approach.

School accreditation has been effective in improving young carer recognition within school settings in the United Kingdom through the Young Carers in Schools (YCIS) initiative¹⁴. The YCIS programme aims to equip schools to identify and support young carers and award schools' commitment to young carers through a tiered award system (Gold, Silver and Bronze). Successfully awarded schools are then mapped on a digital map, enabling young carers and their families to locate carer-inclusive schools for enrolment, which may be best placed to support them throughout their educational journey. Investment in a similar initiative in NSW, drawing on Carers NSW and NSW Government experience developing and implementing the Carers + Employers accreditation program, would enable the NSW Government to continue to champion recognition for young carers in the school system.

Recommendations

- 1.3 Resource the implementation of the updated *Being a Carer, Being a Student and Being a Kid* resource in schools
- 1.4 Invest in the development and implementation of a carer-friendly schools recognition/accreditation program

¹⁰ Cass, B, Brennan, D, Thomson, C, Hill, T, Purcal, C, Hamilton, M, and Adamson, E (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Report prepared for ARC Linkage Partners, October 2011.

¹¹ Due to a relatively small response rate from young carers in NSW, the larger national sample was drawn on in this analysis.

¹² Carers NSW (2022c) *Training and resources for professionals*, available online at: <https://www.carersnsw.org.au/services-and-support/programs-services/young-carers/training-and-resources-for-professionals>, viewed 04 November 2022.

¹³ <https://carersandemployers.org.au/>

¹⁴ Carers Trust (not dated) *Young Carers in Schools*, available online at: <https://carers.org/how-your-school-can-support-young-carers/young-carers-in-schools>, viewed 04 November 2022.

What carers need for improved recognition within service systems

The concept of a NSW Carer Card has been explored in NSW on a number of occasions, with Carers NSW advocating for such measures in several prior Pre-Budget Submissions and consultation opportunities. Carers NSW commends the NSW Government on current initiatives to improve access to the NSW Seniors Card and Companion Card, for which many carers are eligible, including the launch of the digital Seniors Card and the review of the application process for the Concession Card. However, it is important to note that neither of these schemes recognise carers in their own right, and many carers are unable to access them.

An additional NSW Carer Card could be used to identify carers and evidence their eligibility for schemes or rebates addressing costs of living such as reduced transport costs or discounts on goods and services from participating businesses, including holiday and leisure venues, and professional services. Such uses of a NSW Carer Card would recognise the significant financial impacts of caring experienced by carers. The Card could also be used within the health, community and care service sectors as a way of improving carer recognition and legitimising carers' role as a partner in their care recipient's care. This may also support increased inclusion of carers in the planning and implementation of care and support.

During COVID-19, North Sydney Local Health District (NSLHD) implemented a carer identification card for carers to use when attending hospitals within the district during periods of restricted visitation due to COVID-19. Carers in this LHD were encouraged to apply for the card as way to for health staff to identify their caring role. Carers and staff reported that this helped carers to be 'visible' and to navigate the hospital system during a confusing and high-risk period. Extending this concept to all LHDs could assist carers to more easily navigate the hospital system, supporting more effective identification, decision making and discharge, as well as assisting with visitation in scenarios where public health restrictions apply.

In addition to addressing the financial impacts of caring and supporting carer identification and inclusion in care service settings, Carers NSW believes that a NSW Carer Card would also address ongoing challenges carers experience in providing evidence of their caring role in relation to mainstream NSW Government services. For example, when carers are summoned to participate in jury service but cannot fulfil this obligation due to caring responsibilities, the Service NSW website instructs carers to provide a carer's card or similar identification to support their application for exemption. Carers NSW consistently receives enquiries from carers about this requirement, and has contacted the Office of the Sherriff to advise that no such card exists and request that this information be changed multiple times, without response or action.

Another example where a NSW Carer Card could be useful to support access to mainstream services occurred during the COVID-19 lockdown in the second half of 2021, where carers were required to provide evidence in some cases to support their exemption from movement and gathering restrictions under NSW Public Health Orders, or to demonstrate priority eligibility for vaccination. Many carers reported difficulty and frustration evidencing their caring role in these contexts. A NSW Carer Card would have assisted them to do so.

Carers NSW has been working with the NSW Department of Customer Service and NSW Ministry of Health to inform their efforts to improve carer identification and data collection across Service NSW and public health services, and commends the NSW Government for exploring innovative approaches to digital carer credentials. Carers NSW strongly supports this initiative, but stresses the ongoing importance of adequate consultation with carers and expert stakeholders to ensure that the collection and use of data is ethical and effective for carers, the people they care for, and the services both parties interact with. In light of the many recent high-profile cyber attacks occurring in Australia, Carers NSW also stresses the importance of strong cybersecurity measures to ensure that carers can trust the sensitive data collected and shared about their lives and loved ones is stored appropriately.

Recommendations

- 1.5 Progress the review and improvement of the NSW Companion Card application process
- 1.6 Progress ongoing work to improve carer identification in health care and customer service settings
- 1.7 Continue to explore opportunities within emerging digital identity capabilities to improve carer recognition, such as through the implementation of a NSW Carer Card

What carers need for improved advocacy within the disability sector

Carers NSW commends the NSW Government on the establishment of the Disability Advocacy Futures Program (DAFP),¹⁵ an initiative that we believe will be key in ensuring ongoing, adequate disability advocacy across NSW. Carers NSW was also pleased to see that the important role of carers as supporters advocating with or on behalf of the person they care for was highlighted throughout the recent review of disability advocacy in NSW,¹⁶ and that a specific families and carers stream of systemic advocacy was included within the DAFP.

The announcement of the DAFP Service Providers in 2021 provided certainty and assurance of ongoing state-funded disability advocacy. However, Carers NSW notes that the families and carers stream of advocacy still remains unallocated, or the details of the provider have not yet been released. Carers NSW encourages the NSW Government to allocate and/or announce the families and carers systemic advocacy provider in order to enable other carer-focused organisations including Carers NSW to work effectively with the provider to advocate for the experiences and needs of carers of people living with disability in NSW.

Recommendations

- 1.8 Allocate and/or announce the service provider for the carers and families systemic advocacy stream under the Disability Advocacy Futures Program

What carers need in rural and regional areas

The COVID-19 pandemic and recent natural disasters have had far reaching impacts on many people across NSW. However, many of these impacts have been exacerbated for those in rural and regional areas. This includes many carers, given the higher prevalence of disability, illness and ageing in regional areas due to generally lower housing and living costs than in metropolitan areas.

¹⁵ Department of Communities and Justice (2022) *Disability Advocacy Futures Program*, available online at: <https://www.dcj.nsw.gov.au/community-inclusion/disability-and-inclusion/disability-advocacy-futures-program.html>, viewed 04 November 2022.

¹⁶ NSW Ageing and Disability Commission (2019) *Review into disability advocacy in NSW: A report by the NSW Ageing and Disability Commissioner*, available online at: https://www.ageingdisabilitycommission.nsw.gov.au/__data/assets/pdf_file/0008/765530/Review-into-Disability-Advocacy-in-NSW.pdf, viewed 11 October 2022.

The strain on the care workforce resulting from COVID-19, while widespread, has also been more acutely felt in regional areas that were already experience long-standing challenges attracting and retaining workers. This has resulted in increased difficulty for carers attempting to access formal care services and supports, including respite, that enable them to continue providing care.

Pressures related to cost of living are also being acutely felt in regional and rural areas, where housing and living costs have skyrocketed due to the impacts of COVID-19 and natural disasters on labour and supply of goods and materials. Many people in these communities also report a greater reliance on personal transport as a result of limited, adequate public transport options that further restrict access to essential goods and services.

Carers NSW commends the NSW Government on its ongoing commitment to invest in rural and regional initiatives in recent State Budgets, acknowledging the additional challenges faced by those living in rural and regional areas. Carers NSW encourages the NSW Government to continue to invest in rural and regional initiatives, and ensure that carers are identified as a priority group within such initiatives, recognising their vital contribution to regional and rural communities.

Recommendations

- 1.9 Continue to invest in carer-inclusive initiatives focusing on improving outcomes in regional and rural NSW
- 1.10 Ensure that carers are identified as a priority or target group within all rural and regional initiatives

2. Carers need better access to information, services and supports

While many carers choose to take on caring responsibilities, in other cases caring is unexpected and comes on suddenly, giving carers minimal opportunity to prepare. Many carers report challenges with navigating service systems and developing practical caring skills to assist them with providing care safely and sustainably. Furthermore, there are limited opportunities for carers to access formalised training or support with fulfilling their caring role.

Carers NSW believes that through investment in support and capacity building initiatives for carers, former carers and the service systems that they engage with, carers are likely to be better equipped to provide sustainable care, as well as be able to effectively transition out of the caring role, resulting in better long term outcomes for carers and the people that they care for.

What carers need to prevent or reduce abuse and neglect

Investment in supported decision making initiatives

Many carers in NSW support the person that they care for to make decisions, however there are limited opportunities for carers to receive formal training or support with this. The Carers NSW 2022 National Carer Survey¹⁷ found that approximately 83% of NSW respondents provided support with decision making. Furthermore, 90.4% provided support with cognitive tasks, 76.6% with organising finances, 74.1% with handling finances and 82.8% with coordinating support services. Additionally, 73.6%

¹⁷ Carers NSW (2022a).

provided support with communication, 16.7% with interpreting, 73% with advocacy and 91.5% with administrative tasks, all of which can play a key role in making, executing and communicating decisions.

Additionally, while carers often support the person they care for to plan for the future, these discussions can be sensitive, confronting and challenging to navigate. Many carers express concerns about making future care decisions on behalf of the person they care where they may experience reduced decision making capacity, wanting to make the 'right' decision that would align with their will and preference.

The NSW *Carers (Recognition) Act 2010* highlights the role of carers as partners in care who often are experts on the person they care for, and who should therefore be recognised and included in decision making processes, where appropriate. However, in some cases carers will need the skills or tools to effectively participate in these processes. Carers NSW has recently been working closely with a number of experts in this area to identify opportunities to improve the understanding and implementation of supported decision making for carers, as well as professionals and the disability and aged care sectors more broadly.

Carers NSW believes that supported decision making should be considered as an alternative to the appointment of formal guardians, optimising the rights and choices of people with cognitive impairment and minimising the need for tribunals and litigation. However, in order to take a supported decision making approach, community members, including carers and professionals, need to be able to better assess the decision making capacity of individuals and implement best practice support with decision making where they may have limited ability to make decisions themselves.

Education and training are key to building community capacity in supported decision making, and enabling optimal outcomes for carers and those they care for. Carers NSW accordingly recommends that the NSW Government invest in resourcing and expanding effective, evidence-based approaches to upskilling carers and professionals around supported decision making.

Recommendations

- 2.1 Prioritise the implementation of a Supported Decision Making model within NSW legislation in consultation with vulnerable groups, the sector and experts
- 2.2 Invest in evidence-based pilot projects that aim to provide education, resources and support that enable Supported Decision Making approaches

Investment in education and support for carers to prevent abuse and neglect

Carers are often portrayed as potential perpetrators of abuse against vulnerable persons in the community. While it is true that many instances of abuse and neglect involve family members, the recent Aged Care and Disability Royal Commissions have also highlighted the invaluable role of carers as observers and reporters of potential abuse and neglect. Additionally, some carers may be at risk of being victims of abuse themselves.

In some instances, inadequate formal or informal support in the community for carers or the people they care for can lead to carer stress or a breakdown in caring relationships, which can in turn increase the risk of harm to the carer or care recipient. However, little is known about the circumstances in which carer perpetrated abuse may occur, or how it could be prevented. Carers NSW is currently working with researchers from the University of NSW on a project commissioned by the NSW Ageing and Disability Commission (ADC) that aims to address this gap by analysing data regarding carers that are subjects of allegation in reports to the ADC. These findings will then be used to co-develop resources for carers and service providers that are aimed at preventing abuse and neglect from occurring in the community.

So far this project has identified a number of key risk factors associated with carers being subjects of allegation, and associated consultation with carers and key stakeholders has resulted in clear directions regarding how preventative messaging can be distributed among carers and service providers. Carers NSW recommends that the focus on communicating effectively with, and about, carers in the context of reported abuse and neglect continue, in consultation with carers themselves and the experts who work with them. Ongoing monitoring and improvement of the data regarding abuse and neglect, and carers' roles within these situations, will also be important additions to the national conversation about abuse prevention.

Carers NSW also commends the NSW Government on the continued funding of Relationships Australian NSW Let's Talk Elder Support and Mediation Service¹⁸, which we believe provided a valued and effective pathway for resolving potential conflict within families and supports optimal outcomes for people who are ageing and their carers. In addition to securing ongoing resourcing for this important work, Carers NSW believes that the eligibility for such services should also be expanded to carers in their own right, and beyond the ageing context alone to include other caring situations.

However, Carers NSW believes that ongoing investment from the NSW Government is necessary to fund education and support initiatives that build on the findings of current projects and to achieve the aims of reducing abuse and neglect against vulnerable persons in the community.

Recommendations

- 2.3 Continue to resource the development and rollout of evidence-based abuse prevention resources and training to carers, service providers and the wider community
- 2.4 Continue and expand investment in supportive, evidence-based approaches to family conflict resolution such as elder mediation services.

What carers and the people they care for need to participate in NSW elections

Carers NSW recognises the work of NSW Electoral Commission (the Commission) to ensure electoral processes are inclusive and accessible for all citizens. As a member of the Equal Access to Democracy Disability Reference Group, Carers NSW has observed the Commission's ongoing commitment to provide accessible electoral services that meet a wide range of needs, expectations and levels of understanding of the democratic system.

Provisions such as iVote have facilitated greater independence for electors with disability in NSW, including people who are blind or have low vision and people who have reading difficulties or live with other disabilities. However, Carers NSW has concerns about the recent decision not to employ iVote in the upcoming 2023 NSW State Election due to the phasing out of current software. Supportive and accessible electoral processes ensure citizens with diverse access needs can engage in democratic activities independently and can help reduce their reliance on family and friends to participate in elections.

Although inclusive and accessible voting options like iVote support greater independence for electors with disability, many family and friend carers often remain highly involved in supporting the person they care for to engage in democratic activities. Additionally, many carers (37.4% of primary carers) also live

¹⁸ Relationships Australia NSW (not dated) *Let's Talk: Elder Support and Mediation Service*, available online at: <https://www.relationshipsnsw.org.au/support-services/lets-talk-elder-support-and-mediation-service/>, viewed 04 November 2022.

with a reported disability themselves; higher than the incidence of disability reported in the broader population.¹⁹ Limited availability of accessible voting methods may limit the participation and independence of people living with disability, including carers living with disability, in democratic activities. This may also place additional strain on carers to provide support to the person they care for with voting, which can be especially challenging if they do not live nearby or in the same electorate.

For many people with disability, the care provided by family members and friends plays a critical role in supporting their individual wellbeing, community engagement and self-determination. In addition to providing direct personal care and other practical and emotional support, carers are often active in supporting people with disability to navigate, access and coordinate mainstream and specialised services. This includes services aimed at promoting inclusion, as well as supporting participation in the community and in education and employment.²⁰

Carers NSW believes that technology assisted voting options like iVote must be implemented consistently and at all voting locations in future state and local government elections to ensure people with disability, their families and carers can confidently participate in these elections. Where software updates or changes are required for technology assisted voting options in future, greater consideration should be given to when this is done to ensure that it does not coincide with elections, resulting in unavailability that may limit the participation of people with disability in elections. Furthermore, Carers NSW believes that eligibility to use iVote should be broadened to explicitly include family and friend carers as they are likely to be participating in elections alongside or at the same time as the person they care for and may have difficulty participating in in-person voting due to their caring role or own disability.

Recommendations

- 2.5 Continue to resource the review of technology assisted voting and invest in the development of new technology assisted voting mechanisms
- 2.6 Consider extending eligibility for technology assisted voting to additional groups who may benefit from this such as carers

What carers need to prepare for and respond to natural disasters

Many carers have been impacted by recent flooding and severe weather events across NSW, especially in Northern NSW. Effective disaster preparedness and response is key to minimising the impacts of natural disasters,²¹ however current mechanisms are not adequately meeting the needs of carers and the people they care for. Carers NSW welcomes the NSW Government's announcements following the independent review of the 2022 NSW floods and believes that current reforms provide a unique

"Post COVID we had the floods, with no ability or facility to evacuate my mother I believe we were abandoned. I am still struggling with what might have happened if the levy wall had broken"

- Carers NSW 2022 National Carer Survey respondent

¹⁹ ABS (2019).

²⁰ Carers NSW (2020) *Carers NSW 2020 National Carer Survey – unpublished data.*

²¹ United Nations Office for Disaster Risk Reduction (2020) *Words into action: Engaging for resilience in support of the Sendai Framework for Disaster Risk Reduction 2015-2030*, available online at: <https://www.undrr.org/media/43008/download>, viewed 04 November 2022.

opportunity to ensure carer-inclusive disaster preparedness and response.

Holistic and carer inclusive disaster preparedness

Disaster preparedness is key for ensuring that people can respond quickly and appropriately in natural disasters, reducing the risk of injury or loss of life. For carers and the people they care for, preparedness can be even more important, as they may require additional time or support to safely evacuate, especially if the person receiving care relies on life-preserving equipment or requires support with mobility.

Carers NSW has recently established the Care2Prepare project in partnership with the Physical Disability Council of NSW (PDCN) and GoCo,²² with funding from the Australian Government Department of Industry, Science and Resources. Delivered in three locations across NSW from June 2022 to March 2025, the project is aimed at improving household and community resilience and preparedness and reducing the impacts of floods and bushfires. It will focus on building household and community capacity to increase the integration and inclusivity of natural disaster responses for people with disability, older people and family and friend carers in the Central Coast, Shoalhaven and Gunnedah regions.

This innovative pilot project is an important step in improving inclusive disaster preparedness, working directly with carers to support them through a person-centred disaster planning process. However, the project is limited in its ability to provide practical and financial supports that can directly reduce risks in natural disasters, such as property maintenance and essential equipment. For many carers, who are more likely than other Australians to report disability or chronic illness themselves, and the people they care for, property management tasks such as cleaning gutters and clearing vegetation around the home are onerous or too physically demanding to do themselves. Many carers also experience financial hardship, and may be unable to acquire or stockpile essential goods and services to prepare for isolation or evacuation, especially with recent supply shortages and price hikes resulting from the pandemic and natural disasters.

The AIDER (Assist Infirm, Disabled and Elderly Residents) program,²³ delivered by the NSW Rural Fire Service currently provides free property management support to reduce the risk and impacts of bushfires on homes. However, the program is highly under resourced, reliant on volunteers and allows for only a one-off service focusing on reducing bushfire risks. Carers NSW believes that increased practical support with household risk reduction modification and maintenance is key to enabling effective disaster preparedness. Carers NSW therefore recommends that the NSW Government invest in expanding the AIDER program to enable more vulnerable persons to access this service more regularly, and to enable property maintenance and preparation for a broader range of natural disasters, including flooding. Additionally, Carers NSW believes that eligibility for the program should be extended to explicitly include carers, who may be time poor or experience financial constraints that limit their access to private property maintenance services.

Additionally, Carers NSW recommends that the NSW Government invest in a pilot project that overcomes the limitations of the AIDER program. This could include small grants of up to \$3,000, similar to those available through the NSW Return to Work Program, but in this case to fund household risk reduction modification and maintenance, based on assessed disaster preparedness needs.

²² Carers NSW (2022d) *Care2Prepare*, available online at: <https://www.carersnsw.org.au/services-and-support/programs-services/care2prepare>, viewed 04 November 2022.

²³ NSW Rural Fire Service (not dated) *AIDER*, available online at: <https://www.rfs.nsw.gov.au/plan-and-prepare/aider>, viewed 04 November 2022.

Furthermore, local governments are highly involved in broader community preparedness for disasters, overseeing their Local Emergency Management Plan. However, there is currently no requirement for these Plans to be inclusive of people living with disability or their carers. As a result, emergency management provisions may not adequately meet the needs of these groups. Carers NSW believes that the NSW Government must require that Local Emergency Management Plans be inclusive and be prepared in consultation with people living with disability, people who are ageing and their carers. This will ensure that there are adequate provisions within plans that respond to and meet the needs of vulnerable groups in emergencies. The ongoing development of a state-based resilience strategy provides a timely opportunity to enact this requirement.

Recommendations

- 2.7 Increase investment in programs such as the AIDER program that provide practical and financial support with disaster preparedness
- 2.8 Invest in small household preparedness grants to fund household risk reduction modification and maintenance
- 2.9 Explore opportunities to embed requirements for inclusive disaster preparedness within existing mechanisms such as Local Emergency Management Plans

Coordination and inclusion of care and support services in emergency responses

Coordination following emergencies or natural disasters is key in ensuring that essential services continue or are re-established in a timely manner. Following flood events in Northern NSW throughout 2022, carers have reported to Carers NSW limited visibility of care service systems (e.g. My Aged Care, NDIS and Carer Gateway) in flood-affected areas, including within Recovery Centres. This has made it difficult for flood-affected carers to fully understand or access the services and supports that may have been available to them to support them in the caring role. From a public relations perspective, those services/agencies that had not had a presence were noted by the community.

Carers NSW has worked with Resilience NSW to increase the reach of the Carer Gateway services we deliver in the flood-affected regions of Northern NSW, including a presence at Service NSW Recovery Centres. However, this was delayed due to complexities in coordination efforts and limited capacity in Recovery Centres. Carers NSW has now been attending Service NSW Recovery Centres to offer support and while this has been well received, much of the information and referral support has been focused on directing people to other more appropriate service systems or supports (for food, shelter and clothing) and assisting with service navigation.

From Carers NSW understanding, based on findings and recommendations from the independent inquiry into the 2022 NSW Floods, Recovery NSW will be responsible for coordinating and overseeing the response in the first 100 days following a natural disaster.²⁴ Carers NSW believes that as such, Recovery NSW should develop ongoing relationships with Federally funded care and support service systems including My Aged Care, the National Disability Insurance Scheme and Carer Gateway, to enable timely coordination with these agencies during and following emergencies. This will ensure that representatives of these service systems can mobilise quickly following natural disasters to establish

²⁴ NSW Government (2022) *NSW Government Response to the NSW Independent Flood Inquiry*, available online at: https://www.nsw.gov.au/sites/default/files/noindex/2022-08/NSW_Government_Reponse.pdf, viewed 11 October 2022.

an on the ground presence in affected regions and ensure that support is available for affected carers and the people they care for to access, re-establish or increase formal care services.

Furthermore, Carers NSW has heard from carers that within Service NSW Recovery Centres there were limited or no social workers available on site to provide trauma-informed support to persons affected, including carers. While Carers NSW understands that Services Australia, who attended the Recovery Centres, does have some social worker support available, it is not clear if this was made available on the ground when and where it was most needed. Additionally, it has been reported that many carers are still in 'survival mode' and are therefore only able to focus their energy on meeting the essential needs for themselves and the person they care for, including accommodation and food. As such, they have had limited capacity to engage with the mental health supports that are available and they will likely require this support to be available long-term.

Carers NSW strongly encourages the NSW Government to continue to invest in long-term trauma informed mental health services and supports in flood-affected regions. This will ensure that this support is available when carers and other community members are further along in the recovery process and have more capacity to engage with these services and supports to deal with the long-term impacts experienced.

Recommendations

- 2.10 Develop and strengthen relationships with representatives of Federally funded care service systems to enable improved coordination following natural disasters
- 2.11 Embed requirements for the presence of care sector agencies in affected regions following natural disasters in emergency response planning
- 2.12 Invest in increased and ongoing trauma-informed mental health supports in disaster-affected regions

Support to access assistance following natural disasters

In times of crisis, such as natural disasters, governments often invest in a number of initiatives aimed at addressing immediate need, such as pensions and allowances, grants, schemes and rebates. Carers NSW commends the NSW Government on their timely investment in support measures following recent flooding events. However, these initiatives often require individual applications for each, which may limit access to these supports and create a significant amount of additional administrative work for carers who are often already time poor due to their caring role.

Carers NSW staff providing outreach Carer Gateway services in flood-affected regions of Northern NSW have reported that many carers have approached them in Recovery Centres for assistance with navigating different disaster support systems and support completing forms as many are feeling overwhelmed. Furthermore, staff have reported that some carers have needed to use Carers NSW laptops and phones to access this assistance as they either do not own the appropriate digital devices or their digital devices were damaged, destroyed or misplaced as a result of the flooding.

"Needed help from Service NSW post flood. Also federal services at the local flood recovery centre. All took time - bureaucratic hoops to jump through online - way too complicated. Thank God for people - kind, empathetic and helpful to persist x3 to get grant through."

- Carers NSW 2022 National Carer Survey respondent

Additionally, following natural disasters, carers and the people they care for may require a range of specialised supports to enable them to re-establish or continue providing care. Some carers have reported to Carers NSW significant difficulty accessing essentials, including food, medication, and fuel. For carers supporting persons with dietary requirements relating to their medical condition or disability, food hampers or meals provided through community services or charities may not be suitable, meaning that they may have to travel further or to a number of areas to source the food suitable for the person they care for.

Some carers have also reported difficulty funding and sourcing replacement essential mobility equipment and medical devices such as hoists, blood glucose monitors and Continuous Positive Airway Pressure (CPAP) machines. Inability to access this essential equipment may result in an increased need for health interventions into the future and greater long-term negative impacts of flooding on the health and wellbeing of carers and the people they care for.

Carers NSW believes that streamlining and simplifying access to available supports for carers and the people they care for following natural disasters will improve the effectiveness of these initiatives. This may include simplifying and streamlining applications for NSW government grants, schemes and rebates, into one more comprehensive application, which enables access to all relevant initiatives that the applicant is eligible for, with additional information sought where further clarification or assessment of eligibility for additional supports is needed.

Furthermore, Carers NSW believes that the 'request for assistance form' on the Service NSW website should be reviewed to ensure that it collects information about additional vulnerability characteristics such as disability, ageing, chronic illness, mental illness or carer status. Where a person identifies with one of these vulnerable groups, this should trigger additional personalised support with accessing assistance following emergencies, similar to the way in which the RAT Reporting Tool²⁵ referred those at an identified heightened risk of negative outcomes of COVID-19 to NSW Health for additional support. Carers NSW believes that the form should also collect information about needs that may fall outside of mainstream assistance or supports such as the need for assistance with:

- access to essentials including specialised dietary needs related to health conditions or disability and sanitary items,
- access to medications or medical treatment,
- re-establishing formal care services following service disruptions, and
- repairing or replacing medical or mobility equipment due to loss or damage.

Ensuring the form is sensitive to the additional needs of carers and the people they care for will enable the provision of relevant and necessary information, as well as timely referral to the appropriate supports such as Carer Gateway, My Aged Care, the National Disability Insurance Scheme (NDIS), NSW Health and EnableNSW. Providing holistic support with recovery that links carers and the people they care for in with information and the appropriate support as soon as practicable will limit the impacts of natural disasters on these groups and minimise any potential additional strain on carers following crises.

²⁵ Service NSW (not dated) *Register a positive rapid antigen test result*, available online at: <https://www.service.nsw.gov.au/transaction/register-positive-rapid-antigen-test-result>, viewed 04 November 2022.

Recommendations

- 2.13 Invest in streamlining application processes for accessing disaster supports through Service NSW
- 2.14 Review the 'Request for assistance form' in consultation with carers and the people they care for to ensure that it adequately reflects the types of assistance they may need.

What carers need to navigate the ageing journey

An added complexity for people who are ageing and their carers is the intersection between the Federal aged care service system and the many legal and financial processes associated with ageing that fall within state/territory jurisdiction. In NSW this includes, but is not limited to, policy and initiatives relating to retirement villages, consumer rights within aged care settings, guardianship arrangements and future planning, and mechanisms for reporting and addressing elder abuse occurring in the community. Within the disability sector, while still in its early stages, the Disability Gateway aims to provide broader, overarching information and referral support for people with disability across a range of areas, beyond disability care services, no such service exists within the ageing context.

A number of new initiatives stemming from the Royal Commission into Aged Care Quality and Safety may also assist somewhat with service navigation, however these too may be limited in effectiveness. The recently introduced Service Australia Aged Care Specialists²⁶ provide a new opportunity for people to access support around aged care, however Aged Care Specialists are not currently located in all Services Australia sites, and there may be difficulty meeting the high demand for information and service navigation support, especially through upcoming reforms with significant changes to the aged care system expected. Additionally, Care Finders, initially expected to provide broad aged care service navigation support, will now only be available to those who require intensive support with accessing aged care who could otherwise fall through the cracks.²⁷

In prior Pre-Budget Submissions, Carers NSW has argued that there is potentially a place for the NSW Government to provide holistic, face-to-face service navigation support for seniors and their carers to assist with reducing this complexity. The aim would be to provide tailored advice and assistance in accessing and successfully navigating the many services, documentation requirements and legal settings commonly encountered as people age.

One such approach may be the provision of a Seniors Concierge Service, which could be located within Service NSW Service Centres. Drawing on the success of the cost of living navigator service – now the 'Savings Finder' specialist service²⁸ – a Seniors Concierge Service could act as a central point for information and referral for seniors and their carers to enable them to navigate, understand and access relevant age-related services and supports across both State and Federal jurisdictions.

²⁶ Services Australia (2022) *Aged Care Specialist Officer*, available online at: <https://www.servicesaustralia.gov.au/aged-care-specialist-officer-my-aged-care-face-to-face-services?context=55715>, viewed 04 November 2022.

²⁷ Department of Health (2022) *Care finder policy guidance for PHNs*, available online at: https://www.health.gov.au/sites/default/files/documents/2022/04/care-finder-policy-guidance-for-phns_0.pdf, viewed 11 October 2022.

²⁸ Service NSW (2022) *Savings Finder*, available online at: <https://www.service.nsw.gov.au/campaign/savings-finder>, viewed 04 November 2022.

This would complement existing and incoming federally funded aged care service systems and navigation support, which may not fully meet the needs of people who are ageing and their carers. Ultimately, it may enable better integration between state and federal aged care or ageing initiatives, enabling people who are ageing and their carers to better navigate and utilise ageing services and supports.

Recommendations

- 2.15 Invest in a Seniors Concierge Service within Service NSW to assist with navigation of state and federal ageing related services and supports

What carers need to enable sustainability of the social support sector

Not for profit organisations (NFPs) have played a critical role throughout the recent natural disasters and the COVID-19 pandemic and have, as a result, experienced increased and sustained demand for information support from vulnerable community members throughout a prolonged state of crisis. While some carers have withdrawn from services and supports during COVID-19 due to fears of infection risk, many have relied on NFPs for up-to-date information and ever-adapting support. However, throughout recent crises, while the efforts of health workers were recognised and commended, the efforts and impacts for NFP workers have been rarely highlighted or acknowledged.

Continued demands on these organisations to interpret and disseminate information while adapting and expanding their service offerings has placed increasing pressure on sector and workforce sustainability.²⁹ Additionally, NFPs and the social support sector more broadly may be less resourced to invest in restorative social and wellbeing initiatives and activities for staff. In recognition of the significant impacts of recent events on the social support sector, Social Enterprise XFactor Collective, through funding from the Lord Mayor's Charitable Foundation, have committed to establishing Social Sector Wellbeing and Resilience Hub with resources expected to be launched in April 2023.³⁰

In addition to this initiative, Carers NSW encourages the NSW Government to invest in similar initiatives that provide support and resources aimed at improving the health and wellbeing of NFP employees and the social support sector. This includes support and resources tailored to the unique experiences and needs of the NFP sector in NSW such as trauma-informed support for organisations and their staff who have been providing support in regions affected by catastrophic flooding in Northern NSW. Investing in the sustainability of the NFP and social support sector will enable ongoing support for carers in the community across a range of vital areas including formal care, finances, housing and advocacy.

Recommendations

- 2.16 Invest in state-based support and resources aimed at improving the health and wellbeing of workers in the NFP and social support sector

²⁹ Social Ventures Australia and the Centre for Social Impact (2021) *Partners in recovery: Moving beyond the crisis?*, available online at: <https://apo.org.au/sites/default/files/resource-files/2022-09/apo-nid319612.pdf>, viewed 11 October 2022.

³⁰ ProBono (2022) *New hub to care for the carers in response to sector burnout*, available online at: <https://probonoaustralia.com.au/news/2022/06/new-hub-to-care-for-the-carers-in-response-to-sector-burnout/>, viewed 04 November 2022.

3. Carers have improved financial wellbeing and economic opportunities

The rising cost of living is affecting many people in NSW; however, carers face greater financial pressure due to their reduced earning capacity and higher financial costs as a result of their caring role. With the Bureau of Meteorology confirming a third consecutive year of La Niña, carers in some parts of NSW are also facing continued uncertainty and risks of flooding and severe weather events. While for many carers their financial situation was already dire, rising inflation and the expectation of continued natural disasters in the coming months signal the need for action on financial wellbeing. For carers, focus on financial support and improving adequate support services has never been more important.

What carers need for better financial wellbeing

Support to manage the rising costs of caring

While carers experience disproportionate financial disadvantage, record price increases and rising interest rates are taking a higher toll on carers and the people they care for who are less able to absorb financial shocks. The Carers NSW 2022 National Carer Survey found that 52% of NSW respondents reported at least one experience of financial stress in the past 12 months, and 13.1% reported financial distress (four or more experiences of financial stress in the past 12 months).³¹ Additionally, 68.6% reported paying for expenses relating to their caring role such as purchasing medicine and managing the costs of transport and accommodation.³² Carers may also have higher utility costs and wear out white goods more quickly due to additional laundry, heating or cooling necessary to meet the needs of the person they care for.

“... the ever-increasing cost of living presents yet another challenge that carers must confront. It would be helpful if cost of living relief could be provided so that we do not have to eliminate hobbies and treats entirely from our lives. After all, carers cannot purchase themselves a much-deserved reward for their efforts when there is no discretionary money left at the end of each fortnight”

- Carers NSW 2022 National Carer Survey respondent

New research conducted by Evaluate in the *Caring Costs Us* report, indicates that caring has significant impacts on carers' lifetime earnings and their ability to save for retirement. According to the report, primary carers will lose on average \$392,500 in lifetime earnings and \$175,000 in superannuation at age 67.³³ Some people who care for extended periods of time will lose substantially more, with the most affected 10% losing at least \$940,000 in lifetime income, and \$444,500 in retirement savings.³⁴ The report also found that lifetime earnings are reduced by \$39,600 for every year that someone is a primary carer, indicating that for many carers who have been caring from their mid-thirties or forties, there are significant lifetime impacts that may act as a key contributing factor in long term financial insecurity, inequity into retirement, and increases the risk of homelessness later in life.

The consumer price index from June 2021-June 2022 showed that prices rose by 6.1% overall.³⁵ Specifically, fruit and vegetables rose by 7.3%, meat and seafood rose by 6.3%, transport costs rose

³¹ Carers NSW (2022a).

³² Ibid.

³³ Evaluate (2022) *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*, available online at: <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>, viewed 25 August 2022.

³⁴ Ibid.

³⁵ Australian Bureau of Statistics (2022) *Consumer Price Index, Australia*. Available online at: <https://www.abs.gov.au/statistics/economy/price-indexes-and-inflation/consumer-price-index-australia/latest-release#main-features>, viewed 04 November 2022.

by 13.1%, and while rents across Australia have increased between 9% and 10% in capital cities and regional areas respectively, Sydney and Melbourne had record rises for the second quarter in a row.³⁶ For those on low incomes, including government income support such as Carer Payment, the rising cost of living presents significant financial challenges, with people in higher financial stress reporting that they have had to make increasingly difficult and frequent compromises, often choosing between medication, heating, and food.³⁷ Carers NSW has also heard similar reports from carers who have suddenly needed to use charity services for food and clothing, or choose between heating and medication purchases.

Carers NSW commends the NSW Government for providing financial supports for vulnerable groups in the form of financial subsidies, rebates and discount vouchers. Notably, the Pensioner Water Rebate, NSW Gas Rebate, Family Energy Rebate, Public Transport Concessions, and the Taxi Transport Subsidy Scheme. Such initiatives provide targeted, real world supports to enable some low-income groups to better manage financial shocks and the rising costs of living. However, these subsidies are largely restricted to those with a valid concession card, seniors, single parents and low-income families, and therefore often fail to include carers explicitly. Additionally, with no NSW Carer Card currently available, some carers report that it is difficult accessing schemes and rebates available to carers as they have limited recognised evidence of their caring role.

There are a number of actions that could be taken by the NSW Government to support carers amidst rising costs of living. Firstly, the NSW Government could expand the already established voucher schemes available through Service NSW to target carers and provide additional vouchers for groceries and essential items associated with caring to support carers to meet their everyday needs. Additionally, carers should be recognised and prioritised for utility subsidies, and made eligible for public transport concession cards to minimise out-of-pocket costs associated with their caring role. As mentioned earlier in this Pre-Budget Submission, the introduction of a NSW Carer Card would recognise the significant impacts of caring, including financial impacts, and could be implemented to enable carers to access additional support such as concessions and rebates.

Recommendations	
3.1	Expand the Dine & Discover NSW voucher scheme to include targeted supports for carers, including vouchers for essential items such as grocery and fresh produce, and some products available through pharmacies
3.2	Recognise carers as a vulnerable group and as partners in care, and expand eligibility for public transport concession subsidies, including Opal Concession Card, to include carers not currently eligible
3.3	Enable carers to access pre-existing energy rebates—including gas, water, and electricity—which are currently restricted to concession card holders, families and seniors

Investment in carer financial wellbeing

Increasing financial literacy is an important component of improving carers' financial wellbeing and stability. Carers NSW commends the NSW Government for identifying improved carer financial wellbeing and economic opportunities as a priority in the NSW Carers Strategy, and the inclusion of a financial literacy project led by Carers NSW in the first Action Plan. In developing the carer Financial

³⁶ Ibid.

³⁷ NSW Council of Social Service (2022), *Tough Times, Hard Choices: Struggling households and the rising cost-of-living in NSW*. Available online at <https://www.ncoss.org.au/policy-advocacy/policy-research-publications/tough-times-hard-choices-struggling-households-and-the-rising-cost-of-living-in-nsw/>, viewed 04 November 2022.

Literacy Strategy within this project, Carers NSW has a number of areas for further investment by the NSW Government, including opportunities to support carers to understand their finances, educate and provide tools to improve financial planning, and equipping carers with everyday financial tools to support their own financial wellbeing. However, consultation with sector experts suggested that a broader approach focusing on financial wellbeing, as opposed to financial literacy, may be a more effective and contemporary approach to improving carers' financial outcomes.

Carers NSW urges the NSW Government to continue supporting a focus on the financial wellbeing of carers under the second Action Plan of the NSW Carers Strategy. Additionally, while improving carer financial literacy is key element of improving carers' financial wellbeing, this must be complemented by policies programs aimed at improving financial support for carers and carers' employment prospects as financial knowledge alone is not sufficient to overcome the financial disadvantages experienced by carers.

Recommendations

- 3.4 Continue to support a focus on carers' financial wellbeing in the second Action Plan for the NSW Carers Strategy

Carer-focused employment support

A key contributing factor to financial stress among carers is the impact of caring responsibilities on workforce participation. Carers NSW biennial Carer Surveys have consistently shown that carers often reduce their paid working hours or leave the workforce as a result of their caring responsibilities. Australian Bureau of Statistics data (2018) supports the fact that carers experience considerably worse employment outcomes than non-carers, with 52.2% of carers in employment compared with 75.9% of people without caring responsibilities.³⁸

Recent research findings from the NSW Council of Social Services (NCOSS) also suggest that carer employment conditions continue to worsen in NSW, finding that of people with 2 or more jobs, 25% were carers.³⁹ Additionally, research found that 39% of carers were experiencing less job security, with 16% having lost their job, and 40% having experienced reduced hours.⁴⁰ Given the significant barriers to maintaining paid work carers experience, carers may need specialised support re-enter or remain in the workforce.

Carers NSW commends the NSW Government for investing in various employment programs to support vulnerable groups, including carers, but believes ongoing carer-focused job readiness and career support is needed to address the nuanced challenges experiences by carers in the employment context. Carers NSW believes the NSW Government could facilitate this through the development of a streamlined, centralised location for specialised employment supports for carers in the form of a Carers + Employment Hub. This Hub would bring together and build on existing holistic carer-focused employment initiatives delivered by Carers NSW or funded by the NSW Government, such as SkillsLink2Work. This would be a centralised repository of employment resources and supports for carers which would also work to fill a needed gap in employment support for carers given that the only current carer-focused employment support for carers in NSW – the Carer Career Guidance Project and

³⁸ Australian Bureau of Statistics (ABS) (2019) *2018 Survey of Disability, Ageing and Carers, Summary findings*, available: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>, viewed 04 November 2022.

³⁹ NSW Council of Social Service (2022), *Tough Times, Hard Choices: Struggling households and the rising cost-of-living in NSW*. Available online at <https://www.ncoss.org.au/policy-advocacy/policy-research-publications/tough-times-hard-choices-struggling-households-and-the-rising-cost-of-living-in-nsw/>, viewed 04 November 2022.

⁴⁰ Ibid.

job readiness support delivered by Carers NSW as part of Carer Gateway in Northern NSW – are time limited and have defined eligibility criteria, i.e. are not universally available to carers across NSW. The Carers + Employment Hub would run alongside and compliment Carers + Employers which focuses on employers and carer inclusivity in the workplace to create additional pathways between carer-friendly employers and carers seeking employment.

Carers NSW supports the NSW Government's \$32 million investment that aims to support women, including parents and carers, to enter or return to the workforce through the Return to Work Program (RTWP). The RTWP is a forward-thinking approach tackling financial barriers to employment, and while women carers are able to access the funding, male carers—who often experience similar systemic barriers to entering or sustaining employment associated with caring—are not eligible for this support. Furthermore, Carers NSW has heard from a number of carers that accessing the program can take a lot of time and be confusing. It has also been difficult for Carers NSW as a referring organisation to ascertain how the process works and direct referral of clients has not been possible.

Carers NSW commends the NSW Government on expanding eligibility for the RTWP to women carers and including respite in eligible expenditure items. We recommend that this program continue to be funded, but that referral processes be reviewed to further streamline access. Better enabling coordination, collaboration and cross-referrals between RTWP and other similar programs will also increase the efficiency of the supports provided and reduce the administrative burden on carers.

Recommendations	
3.5	Centralise and expand on employment supports for carers through the investment in the development and implementation of a Carers + Employment Hub
3.6	Extend and expand the Return to Work Program, with a continued prioritisation of carers seeking to return to work
3.7	Improve integration of the Return to Work Program with existing carer-focused employment support programs

Ongoing support through 'COVID-normal'

The level of support provided by carers has only risen during COVID-19, with many carers supporting people who are self-isolating and unable to access formal services due to frailty, chronic health conditions, disease and immunosuppression. The impact of the pandemic on carers has been significant, with widespread reductions and cancellations of in-home care services leading to the caring load increasing for many carers during an already stressful period.⁴¹ Despite entering 'COVID normal', carers continue to experience the ongoing effects of COVID-19.

With high rates of COVID-19 vaccination across Australia and decreasing transmission rates in the community, COVID-normal describes the current stage of the pandemic, where government restrictions such as social distancing measures and mask-wearing have been largely eased in an environment in which COVID-19 continues to be transmitted within the community. However, the shift towards a model of 'living with COVID' that forms the basis of 'COVID-normal', belies the continued social and economic impacts of the pandemic on vulnerable groups including carers and the people they care for, and shifts the responsibility for protection from COVID-19 to the individual. A result of this is increased costs for the individual, as carers and the people they care for continue to fund personal protective equipment—

⁴¹ Hofstaetter, L., Judd-Lam, S., and Cherrington, G. (2022). Informal care in Australia during the COVID-19 pandemic. *International Journal of Care and Caring* 6, 1-2, 253-259.

such as masks and rapid antigen tests (RATs)—to enable them to enter and navigate public spaces safely.

Carers NSW acknowledges the ongoing work of the NSW Government to minimise risks for people with disability and people who are ageing and frail, and commends the NSW Government for continuing to promote and deliver free COVID-19 vaccinations and RATs for vulnerable groups. However, Carers NSW believes the NSW Government must recognise the important role that carers continue to play in managing and mitigating the ongoing impacts of COVID-19.

Carers NSW strongly advocates for the establishment of safeguards in the form of increased, flexible, and responsive social, financial, and physical and mental health supports, to allow carers not only to recover from the immediate stresses of the COVID-19 pandemic, but to create a more financially sustainable environment for carers moving forward. Carers NSW commends the NSW Government on initiatives that aim to enable vulnerable groups to access personal protective equipment (PPE) such as RATs, and encourages the NSW to build on this by partnering with local services, such as pharmacies and medical centres to provide ongoing free universal access to masks and RATs. This would reduce out-of-pocket costs and support carers and the people they care for to return to community activities. Carers NSW also acknowledges that the NSW Government responds to the most current health advice, but urges the Government to maintain mask mandates in high risk situations, such as in hospitals and residential aged care facilities.

Recommendations

- 3.8 Continue to invest in campaigns promoting the benefits of the COVID-19 vaccinations, including boosters, and ensure vaccinations are free and accessible
- 3.9 Extend and expand schemes that provide free or subsidised COVID-19 Personal Protective Equipment and Rapid Antigen Tests at key local services, such as pharmacies, medical centres and Service NSW Service Centres
- 3.10 Maintain infection control measures within high risk settings

What carers need to improve housing security

The impacts of COVID-19, natural disasters and rising costs of living have amplified and aggravated existing supply issues in the housing system in NSW. Housing shortages are being felt across all areas of the housing market, including public housing, private rentals, and home ownership.⁴² Lower income earners, including carers and the people they care for, are therefore being edged out of the housing market and are at increased risk of homelessness.

While housing stress and shortages are being felt nation-wide, the highest cost increases and rental increases are being felt in NSW,⁴³ requiring a coordinated government response to ensure carers and the people they care for can access suitable housing and achieve housing security. This has been worsened for those living in flood affected regions. With communities devastated and many forced into temporary emergency accommodation, caravans, and other makeshift accommodation, carers and the people they care have been hardest hit, with most replacement housing inaccessible or not able to meet their needs.

⁴² Anglicare Australia (2022) *Rental Affordability Snapshot: National Report*. Available online at <https://www.anglicare.asn.au/research-advocacy/rental-affordability/>, viewed 4 November 2022.

⁴³ Lang, A (2022) *Sydney suburbs worst hit by rental price hikes*, available online at: <https://www.news.com.au/finance/real-estate/renting/sydney-suburbs-worst-hit-by-rental-price-hikes/news-story/3ba346f3cb412d625d1fa4bc33affa36>, viewed 04 November 2022.

Investment in social housing for carers

Although carers are not an identified priority population for social housing, their financial and welfare situation is similar to those found in other priority groups. In 2020 there were approximately 416,200 households accessing social housing in Australia, supporting approximately 802,000 people, with 98% of residents in the bottom 40% of income earners.⁴⁴ The 2018 Survey of Disability, Ageing and Carers (SDAC) indicated that approximately 36,000 carers live in State managed housing in NSW, with estimates drawing on administrative data from social housing being considerably higher. Furthermore, as at 30 June 2021, there were 44,127 applicants on the NSW Housing Register, awaiting a social housing dwelling to become available.⁴⁵ There were 5,801 applications for priority housing outstanding.⁴⁶ Most allocation zones indicate an expected wait time of at least 5 years, with most allocation zones in Sydney listed as 10+ years.⁴⁷ Where carers of people with reduced mobility require an accessible dwelling to enable them to move through their home safely, wait times can be even longer.

A further challenge for carers is access to appropriate social housing that supports multigenerational caring living arrangements. Many carers are considered 'sandwich' carers, providing care for multiple family members, such as their children as well as ageing parents. Carers NSW recommends greater investigation and analysis of the social housing needs of carers to ensure the development of appropriately sized social housing dwellings that cater for multigenerational families who commonly live together. This will enable family members to share caring arrangements and enable co-habitation of larger family units, which have been found to slow the progress of health conditions, such as dementia.⁴⁸

Carers NSW commends the NSW Government on its efforts to manage complex social housing needs, and acknowledges that long wait times are also due to social housing shortages and availability, but believes more needs to be done to facilitate quicker processing times and increase social housing availability. Carers NSW believes that more investment in suitable, accessible, social housing that is also located in relatively close proximity to health services and other social supports, education facilities, and public transport hubs, is an opportunity to improve support for carers in relation to housing. This will also likely reduce the risk of homelessness or living rough in ageing.

Increased housing accessibility

Home modifications or adaptations can help make existing housing more accessible for people who have reduced mobility or who need increasing support as they age. A recent report from Anglicare Australia, *Ageing in Place: Home and Housing for Australia's Older Renters*, found that only 46% of renters surveyed believed their place of residence would be suitable for an older person with limited mobility.⁴⁹ The Carers NSW 2022 National Carer Survey found that almost one in five carers lived in a home did not meet their needs and was not adequate for the requirements of their caring role.⁵⁰ Carers of people living with disability were more likely to report that their current home did not meet their needs.

Despite many carers reporting significant financial hardship themselves that may jeopardise their accommodation arrangements, many carers also contribute to the housing costs of the people they care for, placing themselves under even greater financial strain. The 2020 National Carer Survey found

⁴⁴ Productivity Commission (2021).

⁴⁵ NSW Department of Communities and Justice (2021), *Applying for housing assistance: expected wait times*. Available online at <https://www.facs.nsw.gov.au/housing/help/applying-assistance/expected-waiting-times>, viewed 04 November 2022.

⁴⁶ Ibid.

⁴⁷ Ibid.

⁴⁸ You, W. & Henneberg, M. (2022) *Large household reduces dementia mortality: A cross-sectional data analysis of 183 populations*, PLoS ONE 17(3): e0263309.

⁴⁹ Anglicare Australia (2022), *Ageing in Place: Home and Housing for Australia's Older Renters*

⁵⁰ Carers NSW (2022a).

that more than one in five (21.4%) of respondents had contributed the housing or accommodation costs of the person they care for, and 13.9% had contributed to the cost of home modifications.⁵¹

The process to secure subsidised home modifications can be time consuming, confusing and easily misunderstood by tenants and home owners, with carers reporting numerous barriers that also differ according to the type of housing. In private rentals, NSW tenants generally require permission from their landlord to make modifications, and while landlords cannot be unreasonable in withholding consent, renters may be required to pay a portion or fully fund modifications. They may also need to finance the removal of modifications when they vacate the property.⁵²

Additionally, carers report ongoing confusion regarding responsibility for the funding of home modifications in social housing dwellings in NSW, especially where a resident receives support through the NDIS. This can make it even more challenging for carers and the people they care for to secure appropriate accommodation. Furthermore, restrictions on NSW Government subsidised modifications in social housing that limit modifications to one instance within a 12-month period can further disadvantage carers and the people they care for who have complex care needs or degenerative conditions.

Carers NSW has heard from carers that, for those who are able to have housing modifications funded within social housing, it may not be possible to get further modifications in a subsequent dwelling, even if the second dwelling is more suitable or is closer to services and supports, reducing the demands of the caring role. Such restrictions limit the independence and mobility of people receiving care and can make caring more difficult, potentially risking injury, as well as requiring carers to participate in protracted administrative processes.

Carers NSW urges the NSW Government to prioritise accessible housing more broadly by adopting the mandatory minimum accessibility standards contained in the revised National Construction Code. Doing so upholds the principle of universal design which forms a key dimension of the NSW Housing Strategy 2041 platform,⁵³ and aligns with Priority 2.7 of the 2021-2022 Action Plan.⁵⁴ Greater investment in accessible social housing dwellings and a requirement to implement universal design in the development of future social housing is needed to ensure that adequate social housing stock is available for carers and the people they care for. Carers NSW also believes that accessibility modifications in social housing needs to be reviewed at a systems level with the aim of streamlining the process, including limiting the need to provide evidence multiple times and supporting carers and the people they care for by ensuring there is a single point of contact throughout the modification process.

Appropriate and adequate emergency housing solutions

The increasing frequency and severity of natural disasters has created greater pressures on housing markets and housing security. Carers are often over-represented in regional or rural areas which are more commonly affected, having purchased or rented homes in disaster-prone regions due to greater housing affordability. For carers, displacement as a result of natural disasters presents unique challenges, which often persist beyond the impacts of natural disasters for people who do not provide care.⁵⁵

⁵¹ Carers NSW (2020) *2020 National Carer Survey*, unpublished data.

⁵² Anglicare Australia (2022).

⁵³ NSW Department of Planning and Environment (2021) *Housing 2041: NSW Housing Strategy*. Available online at <https://www.planning.nsw.gov.au/Policy-and-Legislation/Housing/A-Housing-Strategy-for-NSW>, viewed 4 November 2022.

⁵⁴ NSW Department of Planning and Environment (2021) *Housing 2041: 2021-2022 Action Plan*. Available online at <https://www.planning.nsw.gov.au/Policy-and-Legislation/Housing/A-Housing-Strategy-for-NSW/2021-2022-Action-Plan>, viewed 4 November 2022.

⁵⁵ Bailie, J., Matthews, V., Bailie, R., Villeneuve, M. & Longman, J., (2022) Exposure to risk and experiences of river flooding for people with disability and carers in rural Australia: a cross-sectional survey. *BMJ open*, 12(8).

Many people impacted by flooding events throughout 2022 are currently unable to inhabit their regular dwelling due to water damage or the subsequent development of hazardous mould, forcing many people into temporary emergency housing. While Carers NSW commends the NSW Government for arranging emergency accommodation at short notice, temporary housing such as in Casino and Lismore are often unsuitable for carers and the people they care for given that they may have communal kitchens/bathrooms, are not equipped for accessibility needs, and are positioned out of town with no transport support or access to essential support services.

Carers have also reported rent gouging amongst private rental houses in widely affected regions due to supply shortages. For carers and the people they care for who may require specific accessibility features (e.g. a ramp, wider doorways), there may be no choice other than to pay significantly inflated rent to access a suitable dwelling. Some carers have reported having to move in with other family members, resulting in severe overcrowding of dwellings, while other carers have reported having to move into mobile home villages, which provide very little security of tenure, fewer tenancy rights, and often little or no accessibility features. Carers NSW acknowledges that these circumstances are expected to be temporary, but respectfully reminds the NSW Government that permanent housing solutions are likely multiple years away, leaving carers and the people they care for struggling in unsuitable housing which may increase personal risk of injury. Carers NSW therefore urges the NSW Government to source a greater number of accessible temporary housing solutions, and to prioritise carers and the people they care for in the allocation process.

The NSW Government should be commended for providing some financial assistance with rental costs for those affected by natural disasters,⁵⁶ however there has been significant delays with the roll-out of support packages and carers in particular have reported that the administrative load applying for government flood relief payments to be a significant barrier. Furthermore, carers have reported that for those with significantly inflated rent and those in areas with severe supply shortages, who will not be able to return to their previous dwelling indefinitely, these financial supports are not likely to meet the long-term need. Consequently, carers will likely experience significant financial hardship, in some instances resulting in homelessness, if they are unable to continue to meet their accommodation expenses. Additionally, the onus for financial protection against the impacts of natural disasters is largely on having an adequate level of home and contents insurance. However, the Climate Council has indicated that we are entering an insurance crisis, as properties are becoming increasingly unaffordable to ensure. It is estimated that by 2030, 1 in 25 houses will be uninsurable.⁵⁷

Carers NSW recommends the NSW Government recognise the unique long-term impacts on carers and the people they care for in regions impacted by natural disasters, and urges them to support carer awareness for emergency centres and support accessible emergency housing. Carers NSW further recommends that a targeted approach to long term financial and accommodation support provided to communities in affected regions, with groups such as carers and the people they care for prioritised. Such approaches will help mitigate the impacts of natural disasters by supporting carers in recovery, ensuring carers are able to regain suitable and secure accommodation, limit the financial impacts, and assist in reducing the possibility of homelessness.

⁵⁶ <https://www.service.nsw.gov.au/transaction/apply-flood-recovery-rental-support-payment>

⁵⁷ SBS News (2022), *One in 25 Australian properties will be uninsurable by 2030 due to climate change, report warns*. Available online at <https://www.sbs.com.au/news/article/more-than-half-a-million-homes-across-australia-will-be-uninsurable-by-2030-due-to-climate-change-report-warns/gtrb60q0q>, viewed 4 November 2022.

Recommendations

- 3.11 Prioritise new social housing development allocations for people with existing vulnerabilities, including people with disabilities or who are frail and their carers
- 3.12 Investigate and analyse the social housing needs of carers to ensure the development of appropriately sized social housing dwellings that cater for multigenerational households
- 3.13 Improve and increase accessible housing availability by signing onto the accessibility requirements of the National Construction Code
- 3.14 Source additional temporary housing with greater accessibility features for regions impacted by natural disasters
- 3.15 Prioritise carers and the people they care for in temporary housing allocations, with a focus on accessibility and support service needs

4. Carers need better health and wellbeing

It is well established that the impacts of caring can adversely affect carers' health and wellbeing, especially when there are limited formal and informal supports available. Data from the Carers NSW 2022 National Carer Survey supports the relationship between personal wellbeing and access to necessary services, with many carers citing the impact of limited supports on their physical and mental health.⁵⁸ Carers often prioritise the health and wellbeing of the person they care for, neglecting their own health and wellbeing due to limited time or financial resources. In addition to this, while people receiving care are often able to access subsidised care and assistance, carers themselves may be ineligible for these supports or do not have the energy to seek this assistance for themselves.

The ongoing threat of natural disaster and public health crises has further eroded the options available to carers to prioritise their health and wellbeing, with many carers reflecting that their already limited resources have been redirected to provide additional support to the person they care for or, to meet new costs associated with the after effects of the COVID-19 pandemic or other state of emergency. Further, many existing informal support networks and recreational activities, as well as personal health appointments, have been suspended or compromised due to COVID-19 restrictions or precautions. Although the acuity of COVID-19 has continued to gradually reduce for the broader community, many carers continue to report their behaviours remain largely unchanged in order to protect the people they care for from being exposed to the virus.⁵⁹ As such, carers continue to report feelings of isolation or social disconnectedness, with finite resources available to engage with their community whether in-person or virtually.

"For myself (carer) my health and situation was neglected due to caring role - full time. I lost contact with my community."

- Carers NSW 2022 National Carer Survey respondent

⁵⁸ Carers NSW (2022a).

⁵⁹ Carers Victoria (2022) *Overview of findings from the Victorian COVID-19 carer survey*, available online at: https://www.carersvictoria.org.au/media/4234/2754-carers-vic-overview-of-victorian-covid19-carer-survey_fa.pdf, viewed 29 September 2022.

Carers NSW has raised concerns with the NSW Government about the adequate support of carer health and wellbeing in a number of Pre-Budget Submissions and other consultation opportunities. While Carers NSW acknowledges the ongoing work of the Government to identify and address gaps for carers' health and wellbeing, including investment in health and wellbeing projects delivered by Carers NSW under the NSW Carers Strategy, we would like to highlight some ongoing areas of concern for carers wishing to prioritise their own health needs. Furthermore, Carers NSW has identified a number of opportunities for the NSW Government to overcome these barriers by funding pre-existing initiatives more broadly across NSW, or expanding eligibility for programs or services to include carers.

What carers need to improve their own health and wellbeing

In the Carers NSW Pre-Budget Submission 2022-23, we highlighted the need for carers to be recognised as service users in their own right, noting the importance for the NSW Government to identify and prioritise opportunities that address concerns around reduced carer health and wellbeing by facilitating access to new or pre-existing initiatives where carers are recognised as service users separate to the person they care for.

Carers NSW believes the NSW Government has begun to meaningfully address gaps in carer health and wellbeing, as evidenced in the various initiatives already implemented through the NSW Carers Strategy Action Plan 2020-22. An important consideration that we believe has not yet been effectively addressed however, is how carers can be better supported to actively engage and maintain participation in such initiatives.

"Being able to access GP for myself is costly as I don't qualify for healthcare card, but my finances are a struggle. Have let my health go as everything costs too much."

- Carers NSW 2022 National Carer Survey respondent

As previously identified, many carers experience higher rates of financial distress and insecurity due partly to the additional associated costs with their caring role and limited opportunities to participate in the workforce. Constrained opportunities for breaks from care responsibilities can also prevent carers from engaging in activities that support their own health and wellbeing. As such, we believe the NSW Government has a role in alleviating some of the financial barriers carers experience when seeking to prioritise their own health and wellbeing, and can do so by implementing the following recommendations.

Reduced transport barriers to accessing healthcare

Many carers play a critical role in supporting the person they care for to access healthcare through available schemes and supports, but they can often face significant barriers when accessing healthcare for themselves. Unpublished data from the Carers NSW 2022 National Carer Survey has demonstrated the continued difficulty many carers experience in accessing services that support the prioritisation of their health and wellbeing.⁶⁰ A lack of carer-focused transport options as well as limited eligibility for available transport supports i.e. Taxi Transport Subsidy Scheme (TTSS) and Community Transport Program (CTP), has been identified by carers as a significant, ongoing issue. A lack of suitable and available respite or replacement care options - that is needed for carers to attend health appointments - has also been raised by carers across NSW. Carers NSW has identified a number of opportunities for the NSW Government to overcome existing barriers by funding pre-existing initiatives more broadly across NSW or expanding eligibility for programs or services to include carers.

⁶⁰ Carers NSW (2022a).

Carers NSW has previously raised the need for improved support with transport for carers. A lack of accessible and affordable transport options can significantly impact carers' social and economic participation. However, Carers NSW has recently heard increasing reports from carers that a lack of transport options for carers is limiting their ability to access and participate in health activities, such as attending medical appointments or accessing hospital outpatient treatment.

While we have previously highlighted the importance of addressing carer transport needs, this has often been in the context of advocating for specific carer cohorts. Following, extensive consultation with carers across NSW, it has become even clearer how transport and its accessibility, both from a financial and infrastructure perspective, is critical for carers to prioritise and maintain their health and wellbeing.

Carers report that high costs associated with public transport especially in regional areas can be prohibitive, particularly as many carers remain ineligible for existing transport subsidies. While the NSW Government has implemented various cost saving measures that are available to carers, including the Regional Seniors Travel Card, Carers NSW wishes to highlight that there is currently no carer-specific initiative available. Solutions to addressing transport costs for carers have been explored elsewhere, for example, with the Victorian Government introducing half-priced public transport fares to all carers in receipt of a Carer Card and Carers Myki card, the Victorian Opal card equivalent. Although a Carer Card does not currently exist in NSW, the NSW Government could introduce a similar initiative to reduce the cost of public transport for family and friend carers.

Additionally, as raised in previous Pre-Budget Submissions and consultation opportunities, Carers NSW believes existing initiatives such as the TTSS and CTP could also be broadened to include carers specifically in their eligibility, as these schemes are often accessed by care recipients, but are not available to carers themselves. Furthermore, the ongoing expansion of On Demand public transport services across NSW will also likely provide additional transport options for carers. However, Carers NSW believes that carers should be eligible for concession fares on On Demand public transport services to ensure that potential costs are not prohibitive for carers.

“No services to transport myself to/from hospital for elective surgery as no family/friends able. Have to drive myself home hundreds of KMs after discharge, major surgery and general anaesthetic. I have to get disabled adult daughter to be present in home to 'supervise' minor children, as no respite services ever offered as available, whether in emergency or scheduled.”

- Carers NSW 2022 National Carer Survey respondent

Recommendations

- 4.1 Extend eligibility for transport schemes and rebates to carers to enable them to tend to their own health and wellbeing activities
- 4.2 Invest in transport solutions that support carers to access health and medical appointments
- 4.3 Consider opportunities for replacement care within health settings that enable carers to meet their own health needs

What carers need to reconnect socially

The COVID-19 pandemic has demonstrated the impact of sustained social isolation, especially on those who depend largely on face-to-face models of social support. The Carers NSW 2022 National Carer Survey found that nearly three in five carers are highly socially isolated and an additional one in five carers have low levels of social support.⁶¹ Additionally, throughout the pandemic, extensive consultation with carers facilitated by Carers NSW has highlighted that carers require more support to maintain social connection with their peers and broader community.

Research indicates that connecting with peers and sharing experiences can significantly reduce feelings of isolation. However, not all carers are able to engage with traditional models of peer support or have the confidence (or capacity) to navigate online equivalents. Many carers – especially those in regional or remote communities – may not have access to the digital infrastructure required to connect to their communities online.

Carers NSW recognises the work of the NSW Government to address ongoing and emerging issues related to social isolation among carers and the community more broadly. While the Government has introduced initiatives to improve social connectedness, such as the Reducing Social Isolation for Seniors Grant Program, these programs are often cohort specific and as such do not service all members of the community. Furthermore, with the ongoing risks associated with COVID-19 in the community, many carers are not yet comfortable to return to face-to-face social activities, however have limited personal access to device or computer to participate in online initiatives.

Access to appropriate technology and equipment varies considerably among carers, with some without any device or computer at all. Carers NSW has also heard that many carers are reportedly waiting for services to resume face-to-face engagement and not participating in the online services available. Carers NSW encourages the NSW Government to invest in carer-focused and carer inclusive measures that support carers reconnect with their communities and reduce the impacts of social isolation.

"I'd have liked to access some online services but don't have internet at home due to cost and old computer. No money to buy a new one."

- Carers NSW 2022 National Carer Survey respondent

Expanded digital literacy programs

In response to the lack of carer specific digital support programs and noting the impact of long-term isolation on carers as a result of the COVID-19 lockdown, Carers NSW partnered with YourLink to establish the 'Connecting Carers Online' digital literacy project. The program has been delivered to nearly 200 carers since mid-2021 as part of our Carer Gateway service offerings in the Hunter New England, Central Coast and North Coast regions. The project has simultaneously bridged multiple access gaps for carers by providing each participant a smart device and data plan, connecting them with online training sessions to build their skills and confidence, and providing opportunities to connect socially with other carers as well as family members and friends through meaningful activities.

Based on analysis of data from the first 70 carers to complete the program, 94% of participants agreed that the training met or exceeded their goals.⁶² Many carers also reported the broadening of the digital literacy skills, in addition to receiving a device for their own personal use, afforded them greater independence and ability to connect with their peers in new and alternative ways.

⁶¹ Carers NSW (2022a).

⁶² YourLink (2022) Creating life-changing opportunities for carers through digital skills: Carers NSW case study, available online at: <https://www.yourlink.com.au/carersnsw-case-study>, viewed 04 November 2022.

Carers NSW wishes to highlight that there are many other carers within our Gateway service region and in NSW more broadly who would benefit significantly from this program, but due to program-based funding and locational constraints are ineligible to participate. To ensure all carers across NSW can access services and supports irrespective of where they live, we recommend that the NSW Governments consider broadening the scope of existing grant opportunities such as the Reducing Social Isolation for Seniors Program to allow for larger scale projects like Connecting Carers Online to be delivered state-wide.

Furthermore, given the increasing cybersecurity risks within the community, Carers NSW believes that the NSW Government should also invest in additional resources and education for carers regarding identifying and preventing online scams. Carers are often already financially vulnerable, therefore proactive measures to reduce cybersecurity risks is likely to result in optimal financial outcomes for carers.

Recommendations

- 4.4 Invest in a state-wide carer-focused digital literacy and digital access program
- 4.5 Continue to explore opportunities to fund or subsidise digital devices for financially disadvantaged groups such as carers to support social connection online
- 4.6 Invest in additional education and resources for carers to reduce the risk of financial losses due to online scams or cybersecurity risks

Increased opportunities for in-person peer support

Peer support is an important element of support for carers, with carers reporting high regard for opportunities to be able to share their experiences with, and receive understanding and guidance from, other carers in similar circumstances. Carers NSW recognises the existing peer support options available to carers through Carer Gateway and believes these services will encourage carers to build and maintain meaningful relationships with their peers both online and in-person. However, the Carers NSW 2022 National Carer Survey found that while many carers were accessing peer support, almost 2 in 5 reported needing more face to face peer support and 1 in 3 reported needing more online peer support.⁶³ These findings suggest that there are some limitations to existing peer support models that can be addressed at a state-level to strengthen existing peer support services across NSW.

While Carer Gateway links carers to each other to establish new peer support groups, many peer support groups have identified there is no funding available to support their longer-term incidental costs. For example, Carers NSW has heard indirectly from group facilitators that they have resorted to holding meetings at their private residences or locations such as cafes to ensure access for all group members. Although group facilitators have explored options to obtain funding that would allow them to book private rooms, organise guest speakers and pay for small-scale capacity building activities, many report to

"We used a carer support group where we got together and did some sort of funded activity. This is no longer available causing more isolation in the carer community."

- Carers NSW 2022 National Carer Survey respondent

⁶³ Carers NSW (2022a).

Carers NSW that such grant options exclude applications made on behalf of individuals or small informal groups unless they are auspiced through registered companies.

Based on data collected through previous peer support programs overseen by Carers NSW, we are aware of over 300 carer peer support groups – many of which have been in operation for a number of years – that are likely to experience difficulty continuing due to the slow reduction of funding (which is used to support their maintenance) and their inability to receive this support alternatively through Carer Gateway. Further, following the establishment of a peer support group through Carer Gateway, there is finite support available to group facilitators to physically maintain the running of the group or to receive ongoing guidance. While Carers NSW has capacity to provide some direction and assistance to peer group facilitators through our role as a peak organisation, we are unable to offer this support to all groups across NSW following the cessation of the Carer Peer Connect program in December 2021.

Carers NSW wishes to acknowledge that despite the limitations of the current peer support model within Carer Gateway, many carers – especially those who are new to the caring role – will benefit significantly from the peer support services available to them. However, we believe there is scope for the NSW Government to support existing and emerging peer-support groups maintain their function.

To support existing carer support groups to maintain their function, the NSW Government could introduce small grant opportunities, similar to the recently announced Carers Support Group Resources Fund in Victoria,⁶⁴ which will provide up to \$5,000 to every carer support group across the state for a range of purposes. Carers NSW believes that ensuring the sustainability of carer peer support groups will enable the development of stronger, more productive relationships and support networks that minimise social isolation for carers.

Recommendations

- 4.7 Invest in a small grants program for carer support groups to meeting ongoing costs of facilitating carer support groups in NSW

What carers need to address the long-term impacts of COVID-19

With reduced access to formal services and supports, increased isolation and a feeling of being inadequately supported in the reduction of precautionary COVID-19 public health measures, carers have reported significant impacts of COVID-19 on their health and wellbeing. Following a prolonged period of increased and intensified caring responsibilities throughout the pandemic, many carers report that they have reached or are nearing their 'breaking point'.

"Have definitely let slip self-care with the challenges of COVID."

- Carers NSW 2022 National Carer Survey respondent

Carers NSW has heard anecdotally from carers and service providers that carers' health is declining as they have been unable to attend to their own health for an extended period. Additionally, multiple carers have reported the impact of prolonged ill-health following COVID-19 infection. Their experience of 'long COVID', in conjunction with increased caring responsibilities, has reduced the capacity of some carers

⁶⁴ Tim Bull MP (2022) *More support for carers and social enterprise start-ups* [Media Release, 16 October 2022].

to physically recover and sustain immunity against further infections and co-morbidities, compromising their right to health and wellbeing in the long term.

Carers impacted by long COVID have reported to Carers NSW significant difficulty accessing care and support in their own right, often not meeting the eligibility criteria for existing ageing or disability service systems based on their long COVID symptoms. Carers have also reported challenges accessing adequate formal care to replace the care that they can no longer provide as a result of long COVID. While Carer Gateway can provide short-term solutions in these situations, it is limited in its ability to provide ongoing care that meets carer and care recipient needs.

Carers NSW believes that the NSW Government must ensure adequate care is available in the community for carers affected by long COVID, including where a carer, the person they care for, or both require additional care and support. This could be achieved by establishing short term community-based care packages, similar to COMPACs, delivered by NSW Health, that could be accessed by people experiencing significant impacts of long COVID. It will also likely involve collaboration between State and Federal governments to determine long term solutions aimed at ensuring that the care needs of people with long COVID, including carers and the people they care for are met through new or existing service systems.

Carers NSW has significant concerns about the sustainability of caring arrangements due to poor self-reported health and wellbeing of carers at this time, which may result in an increase in premature residential aged care placements. Premature placements in residential aged care create significant avoidable costs and can place additional psychological strain on carers and the people they care for.

Maria* cares for two children living with disability and her mother who is ageing and lives with chronic health conditions. Maria contracted COVID-19 in 2021 and has experienced ongoing symptoms including fatigue and shortness of breath, which is believed to be associated with long COVID. Maria has had difficulty continuing to providing care due to the impacts of these symptoms, however has been unable to access additional ongoing support with providing care as Carer Gateway can only provide short term assistance with care and she is not eligible for any subsidised disability or care services on her own behalf as long COVID does not currently meet eligibility requirements for support. Maria has also experienced difficulty accessing additional formal services that substitute the care that she is not currently able to provide. Maria is concerned about the ongoing sustainability of her caring roles and the impact of this on her family.

**Name changed for privacy*

Recommendations

- 4.8 Invest in short term care and support packages that meet the care needs of carers and the people they care for with long COVID
- 4.9 Develop and implement a long-term carer-inclusive strategy for addressing the care and support needs of carers and people receiving care with long COVID

CONCLUSION

This Pre-Budget Submission has highlighted 50 recommendations for the NSW Government to invest in improving the recognition, inclusion and support of carers in NSW, in line with its existing commitments under *NSW Carers (Recognition) Act 2010* and *NSW Carers Strategy: Caring in NSW, 2020 – 2030*. Carers NSW welcomes the increasing attention being paid to carers across the NSW Government and looks forward to continuing to work closely with its departments and agencies, as well as other external stakeholders, in progressing innovation and impact in a range of key areas.