



Caring through crisis

Carers NSW Pre-Budget Submission 2021-22

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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¹ Australian Bureau of Statistics (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.

INTRODUCTION

2020 has brought numerous challenges to the people of NSW and to the NSW Government. Carers have been among the many NSW residents adversely affected by flood, bushfire and the COVID-19 pandemic and are experiencing significant associated 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 in NSW 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 10 years of the NSW *Carers (Recognition) Act 2010*, the launch of the new NSW Carers Strategy: *Caring in NSW 2020 – 2030*, the delivery by Carers NSW of the first National Carer Survey, and the launch of the new Carer Gateway services across Australia, Carers NSW seeks to draw on learnings from the challenges of 2020 to inform Government expenditure into the next financial year.

Carers NSW anticipates that by 2021-22, Carer Gateway services will have been in place long enough for the new system's strengths and shortcomings to be clearly identified. The final outcomes of the Royal Commission into Aged Care Quality and Safety will have also been released, with likely implications for older people and their carers in NSW, with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the Productivity inquiry into Mental Health having further progressed in their scrutiny and planned reform of these two service systems.

By 2021-22, the new NSW Ageing Strategy will have been implemented, and the first year of the NSW Carers Strategy Action Plan 2020-22 will be well underway, providing significant opportunity to engage older people, carers and the organisations that support them in NSW to recognise and act on the support needs apparent following the many challenges of 2020.

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 Government investment: carer recognition, emergency response, future planning and financial security. 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 new NSW Carers Strategy. This Pre-Budget Submission makes a range of practical recommendations for how these important principles can be progressed in the 2021-22 Budget Period.



1. Continue to champion carer recognition



2. Include carers in crisis responses



3. Support carers to plan and prepare



4. Improve carers' financial security

1. CONTINUE TO CHAMPION CARER RECOGNITION

The NSW Government has undertaken many initiatives in the past decade to reflect its commitment to improving the recognition of carers. Significantly, May 2020 marked the ten-year anniversary of the *NSW Carers (Recognition) Act 2010* (the Act). While the Act does not create legally enforceable rights for carers,¹ Carers NSW has certainly observed that the enacting and implementation of this historical legislation has increased awareness within the public sector and community of the importance of recognising carers.

2020 is also a significant year for carer projects and initiatives, with the second NSW Carers Strategy: *Caring in NSW 2020 - 2030* (the Strategy) being launched on 12 October 2020. The ten-year, whole-of-government Strategy indicates the NSW Government's long-term commitment to furthering carer recognition, inclusion and support in NSW, and the in-depth co-design process for the Strategy built on the consultations conducted for the last Strategy, dated 2014-2019, increasing direct engagement with carers.

This section examines key ways in which the NSW Government can continue to champion and advance carer recognition as NSW enters a new decade.

Progress a strong Carers Strategy

The new NSW Carers Strategy: *Caring in NSW 2020 - 2030* and accompanying 2020-22 Action Plan were released during National Carers Week on 12 October 2020. Carers NSW strongly supports the Strategy's principles and priorities, and commends the NSW Government's extensive co-design in developing these documents. Carers NSW own consultation and research has identified consistent key themes and areas for improving carer outcomes and looks forward to working closely with the NSW Government over the next ten years in achieving its vision for 2030.

Specific recommendations relating to the four priority areas of better information and support, increased recognition and empowerment, improved financial wellbeing, and improved health and wellbeing² are included throughout this submission. Carers NSW also has further recommendations regarding the implementation and oversight of the Strategy itself, which will be explored in this section.

A well-resourced Strategy

Carers NSW is strongly supportive of the concept of a whole-of-government Carers Strategy built on extensive consultation with carers and other key stakeholders. However, in order for the Strategy to succeed, we believe it needs to facilitate continued funding for innovative projects supporting carers in NSW, especially as most of its existing Carer Investment Program (CIP) grants will come to an end by the time of the next State Budget.

The \$5.6 million in CIP funding has enabled Carers NSW and a range of other non-government organisations and government agencies to implement practical, evidence-based support for carers that addresses identified gaps and supports the achievement of the objectives of the Act and the previous Strategy.³ Some of the many achievements enabled by this funding include:

- Driver mentoring for young carers working towards their licence through the YC-Drive project delivered by Carers NSW
- Ongoing support for 688 carer support groups across NSW through online training and facilitator meetings delivered by Carers NSW through the Carer Peer Connect project
- Support for carers seeking to return to paid work through the Care2Work project delivered by Carers NSW
- The first carer-focused research centre in the country, established through the University of Technology, Sydney's Institute of Public Policy and Governance

- Support for carers to recognise their current skills and develop a program of study through TAFE through the Upskilling Carers project

Grants for the above projects generally end in June 2021, and while some activities may be able to continue in some form, it is critical that the next State Budget ensures that successful existing activities and other new, innovative activities that can help achieve the Strategy's aims are adequately funded into the future.

Adequate resourcing of awareness raising and evaluation activities in regard to the Strategy will also be critical in ensuring its effectiveness and impact in NSW, as explored in subsequent sections of this submission.

A well-integrated Strategy

Other relevant strategies and frameworks should be considered together with the new Strategy so that any possible synergies and cost efficiencies can be identified. In particular, the new NSW Ageing Strategy will be launched in 2021 following a similarly extensive consultation process. One in four carers in NSW (24%, or 207,000 carers total) are aged 65 years and above, and most (56%) of the 691,800 NSW residents over the age of 65 who need assistance receive at least some of that assistance from family members and friends.⁴ Given the large numbers of carers who are ageing themselves, or caring for someone who is ageing, it will therefore be critical that the priorities and funded activities to deliver the NSW Ageing Strategy complement and support those of the NSW Carers Strategy.

Another key framework that should be integrated into work conducted to support the NSW Carers Strategy is the Regional Youth Framework, which defines whole-of-government priorities supporting mentally and physically healthy, work-ready, connected and valued young people in regional NSW. More than one in five young carers in NSW lives outside of a major city,⁵ and a number of participants in Carers NSW recent Young Carer Research Project were from regional and rural areas and noted the distinct challenges of being a young carer in those locations.⁶

While both young carers and carers living in regional, rural and remote areas are recognised as particular target groups under the NSW Carers Strategy, there is minimal emphasis on either group in the first Action Plan. Partnering with the Office for Regional Youth on the implementation of the Framework therefore presents the opportunity to improve support to these two priority groups.

A third key framework with particular relevance to the Strategy that will be implemented in the next State Budget period is the new National Disability Strategy, including the NSW Ageing and Disability Commissioner's oversight of its implementation in NSW. The new National Disability Strategy is currently still in development at the time of writing, with submissions to the latest round of consultation closing on 31 October 2020.

In partnership with Carers Australia and the National Carer Network, Carers NSW has recommended that the National Disability Strategy be explicitly carer-inclusive but also be complemented by a stand-alone National Carer Strategy that complements its equivalent strategies in each state and territory.⁷ These developments should be closely monitored by the NSW Government in order to ensure that State-based implementation activities are consistent and carer-inclusive.

An effective Strategy

There is limited Australian evidence on what types of interventions work best to support carers. As the Strategy contains and supports a range of innovative carer projects, it is imperative that quality data be consistently captured in order to demonstrate the effectiveness of these interventions and enable learning and continuous improvement, as well as the overall expansion of the national and

international evidence base. Carers NSW therefore recommends that a robust, independent evaluation plan for the Strategy commence early on to ensure that this data is consistently captured. Reporting intervals should be frequent enough that progress and learnings can be shared publicly and result in continuous improvement.

Effective Strategies also need powerful champions. Despite many carer focused activities being led by the NSW Government, the legislated establishment of a NSW Carers Advisory Council (consistent with formal advisory bodies that exist on both ageing and disability) and despite the Opposition's inclusion of a series of Shadow Ministers for Carers, the NSW Government continues not to name carers in the title of the relevant Minister's portfolio. Carers NSW strongly recommends that there be a Minister for Carers, whether independently or combined with other relevant portfolios, such as Disability and Ageing. Without this explicit recognition, carer-specific initiatives are likely to receive less awareness within NSW Parliament, the public sector and the community.

Recommendations

- Provide continued funding for new and existing innovative projects supporting carers in NSW
- Adequately resource the Strategy to enable broad, creative promotion to maximise awareness
- Complement and build on other relevant strategies and frameworks
- Embed a strong, independent and transparent evaluation plan in the delivery of the Strategy
- Improve oversight and visibility of the Strategy by naming a Minister for Carers

Build on the success of 10 years of carer recognition legislation

2020 marks the ten-year anniversary of the NSW *Carers (Recognition) Act 2010* (the Act), a ground-breaking piece of legislation for NSW that has led to increased awareness of the needs and experiences of carers in the public sector and broader community. The 2021-22 financial year will be a key time for the NSW Government and carers in NSW to build on these achievements in NSW and further strengthen carer recognition.

Increase public sector accountability

Carers NSW has been working closely with the NSW Department of Communities and Justice (DCJ) since 2010 to raise awareness of, and increase compliance with, the Act within the NSW public sector. Carers NSW commends DCJ's efforts in promoting the legislation and the NSW Carers Charter (the Charter) to carers, the public sector and the broader community, but notes that many NSW Government departments and agencies continue to have limited awareness about the Act and their obligations.

This is evidenced in continued case studies and research evidence identified by Carers NSW that indicates many carers engaging with NSW Government departments and agencies - as both service users and employees – do not believe that the Charter has been upheld in their individual situation. Unfortunately, as the Act does not create any additional legal rights for carers,⁸ and as there is no formal complaints mechanism tied to the implementation of the Charter, there is often little recourse for carers in this situation.

As noted in our submission to the 2016 review of the Act,⁹ Carers NSW supports greater accountability of Government departments and agencies in relation to their legislated obligations. Carers NSW supports DCJ's increased scrutiny of annual public sector reporting in line with the Act's

requirements as well as its recent commissioning of research to better understand which parts of the public sector are performing particularly well in implementing the Act and Charter. Carers NSW looks forward to the findings of this research and believes that greater promotion of best practice in relation to carer recognition within and outside the public sector will result in continual improvement.

Departments and agencies that achieve accreditation under the NSW Government funded Carers + Employers program, led by Carers NSW, also have great potential to influence other public sector entities in taking practical steps to improve support for employees who are carers, a key component of public sector obligations under the Act. Carers NSW therefore supports the initiative included in the 2021-22 Action Plan to promote the Carers + Employers Program to NSW Government agencies and commends those departments and agencies who have already achieved, or are progressing towards, accreditation.

Help carers feel recognised

While actions taken within the public sector to better recognise and support carers should be recorded, celebrated and shared with others to inspire best practice, these initiatives do not always 'trickle down' to impact the individual circumstances of carers in the community.

Since the implementation of the Act, Carers NSW has included questions in our biennial Carers NSW Carer Survey to gauge the impact of the Act on recognition in NSW over time. In the past few surveys, carers' self-reported sense of being recognised and valued in their caring role has remained relatively low and consistent, with approximately 27% respondents agreeing that they felt recognised and valued as carers.¹⁰

In the 2020 National Carer Survey, carer recognition was broken down into recognition in a range of different contexts, in order to identify which settings were exhibiting progress or lagging behind with regard to carer recognition. In NSW it was encouraging to note that well over one in three respondents (37%) indicated being recognised and valued as a carer by service providers (see Table 1). While the type of service provider was not specified in this question, in NSW many service providers are either NSW Government entities or receive NSW Government funding, bringing them within the Act's jurisdiction.

Table 1: Carer recognition by community, service providers and government (NSW)¹¹

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Recognised by community	4.7%	19.7%	26.4%	26.8%	22.3%
Recognised by service providers	8.2%	28.5%	29.7%	20.1%	13.5%
Recognised by government	3.4%	13.6%	28.1%	21.3%	33.6%

Only one in four NSW respondents (24%), however, indicated that their community recognised and valued their caring role, and even fewer (17%) self-reported a sense of recognition and value from government, suggesting that ongoing initiatives to increase government and community recognition of carers still have considerable room for growth. It should also be noted, however, that the Survey question did not specify a particular level of government, and that these findings cannot necessarily be attributed to the NSW Government. What these findings do indicate is that carers' general awareness of what governments are doing to recognise and support them is limited. Carers NSW looks forward to continuing to work with DCJ in identifying how best to ensure that government initiatives are visible and impactful to carers in NSW, both individually and collectively.

Increasing transparency and plainer language communication of what NSW Government departments and agencies are doing to implement the Act and Strategy may assist carers to identify that progress is occurring. Carers NSW recognises that the carer pages on the DCJ website have continued to improve and now provide simple, easy to navigate information about what the NSW Government is doing for carers. However, we also note that it is challenging to find these pages from the DCJ landing page, especially due to the use of 'carers' in other contexts that fall within the Department's jurisdiction, as discussed later in this submission.

"Promote further community awareness of the contribution that carers make and their experiences. Make them more visible and recognised in society."

- Respondent to Carers NSW
2020 Pre-Budget Submission
Stakeholder Feedback Form

DCJ has engaged carers extensively in the co-design of the new Strategy, and Carers NSW urges this level of engagement to continue as the first Action Plan is implemented and as reporting and evaluation findings emerge. Straightforward collateral promoting the Strategy's achievements with a community audience in mind, leveraging social and regular media channels, could achieve greater awareness and self-reported recognition among carers. Conveniently, the two-year Action Plan periods also correspond with the frequency of the biennial Carers NSW Carer Survey, which will repeat its 2020 carer recognition questions again in 2022, acting as a helpful measure of change over time.

It should also be noted that carers often report to Carers NSW that what makes them feel recognised is being able to access the support they need when they need it, including, and especially, financial support. This was a theme that particularly emerged from consultations conducted by Carers NSW during the height of the COVID-19 pandemic in NSW.¹² While not all forms of direct carer support and financial support are within the NSW Government's jurisdiction, ensuring that carer support gaps are identified and addressed may assist carers to feel more recognised by government and community.

The new Service NSW website landing page for carers, pop-ups for carers in Service NSW centres, and carer-specific support through Service NSW Cost of Living Specialists, all part of the 2020-22 Action Plan, are a positive start in better centralising service information for carers and supporting that information with tailored, in-person assistance.

Uphold carer rights

Another way in which carers frequently report to Carers NSW that they feel recognised is when they are explicitly invited into, and listened to in the context of, service planning and implementation. Carer inclusion in the context of health and mental health services is explored in the next section, but has also been examined in depth as part of the Carer Rights & Complaints Network (CRCN) initiative, led by Carers NSW in partnership with DCJ since 2017. Carers NSW is pleased to see that carer rights education is a key part of the first Action Plan under the Strategy, and looks forward to building on the CRCN's first substantial output, a series of carer rights fact sheets released during National Carers Week 2020, in partnership with DCJ and the other CRCN member agencies.

In addition to raising awareness among carers of their rights and complaints options, Carers NSW also urges DCJ to support the broadening and strengthening of carer rights within NSW and Commonwealth led service systems and complaints pathways to improve carer outcomes overall. While the inclusion in the 2020-22 Action Plan of training for mental health clinicians in regard to carer rights, advocacy training for mental health carers and a revision of the NSW Health *Key Directions* document promise to increase the capacity of carers and key State-funded service providers in recognising and upholding carer rights, further strengthening of the NSW *Carers (Recognition) Act* and strengthened, more carer-inclusive State-based complaints and individual advocacy opportunities in relation to these and other service sectors should also be a priority.

Clarify carer terminology

Carers NSW commends DCJ on its various community awareness initiatives, engaging the media to elevate the voices and experiences of carers in NSW. However, stigma and misunderstanding of carers persists, with a key cause being the inconsistent use of the term 'carer' within the NSW Government. Despite the specific definition included in the Act, it is still very common for 'carer' to be incorrectly used to refer paid care workers, foster and kinship carers, parents of children without additional needs, and family members who are not in a caring role (especially in the context of abuse). For carers to be identified, recognised and connected with support, the definition and usage of the term 'carer' needs to be consistent, starting with the NSW Government departments that engage most with carers: DCJ and NSW Health.

While this is a national problem, there is much the NSW Government could do to improve this by being more consistent and accurate in its own use of these terms. Carers NSW suggests a public information campaign focused on the definition of the term 'carer', addressing common misconceptions, as well as an internal audit of the use of the term 'carer' within the NSW Government in order to identify areas in which staff education, resources and even other legislation and frameworks may need to be updated.

A key starting point should be a review of the labelling and navigation of carer-related information on the DCJ website. While the information on and for carers is strong, the landing pages for FACS and DCJ highlight foster care information, with 'carer' being used to address both groups, and information addressing carers according to the Act definition being less prominent.

Recommendations

- Capture and widely promote best practice initiatives in carer recognition within the public sector
- Communicate progress against the Act and Strategy to carers in plain language on a more regular basis
- Monitor and respond to gaps in carer support to ensure carers feel recognised and supported
- Work to strengthen carer rights and streamline complaints processes to better support carers
- Raise public awareness of the legislated definition of carers to reduce confusion over, and misuse of, the term
- Monitor and correct inconsistent usage of carer language within the NSW Government

Improve carer inclusion in health and mental health services

Carers access health services both as patients themselves and with, and on behalf of, the people they care for. In both cases, health services can be complicated to access and may not meet patients' needs. Many patients rely on family members and friends to assist them in accessing health services, and many more are discharged into the care of family members and friends at home and in the community.

Adequately funded, carer-inclusive health services are therefore critical in sustaining informal caring arrangements and supporting carer health and wellbeing. In addition, the NSW Carers Charter stipulates that carers are partners in care, and their choices, views and needs should be taken into account in the assessment, planning, delivery and review of services provided to the people they care

for.¹³ As such, carers require increased support, information and resources to better navigate the health system in support of the person they care for.

Carers NSW commends the NSW Government on including a number of initiatives within the 2020-22 Action Plan focused on improving carer recognition in the health, mental health and drug and alcohol sectors. This section explores how carer recognition and support in these sectors can be further prioritised.

Identifying carers' own health needs

One key way in which carer recognition can be improved in the health and mental health sectors is by formalising the acknowledgement that carers may require targeted support in order to have their own health and wellbeing needs met. Carers are known to neglect their own health care due to prioritising the health of those they care for, and this along with the physical and emotional challenges of caring results in a higher than average rate of disability, chronic health conditions and emotional distress.¹⁴

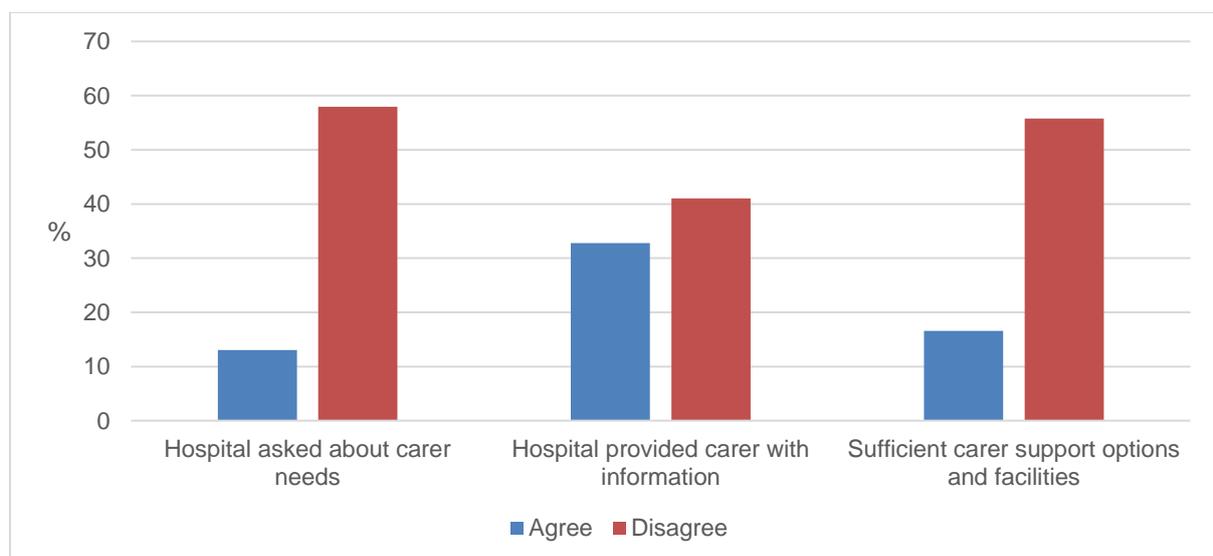
"I don't think the government acknowledges the fact that carers lives come second after the needs of the person being cared for."

- Respondent to Carers NSW 2020 Pre-Budget Submission Stakeholder Feedback Form

The individual health and wellbeing of carers is imperative to the social and economic sustainability of care in the home and community. When carer health and wellbeing is at risk, there is a greater chance of carers losing the capacity to care or being absent from the home to engage in treatment. The temporary or permanent reduction in capacity to care has an impact at the individual, community and sector levels, including implications for personal relationships, community and health services, and health budgets.

According to the 2020 National Carer Survey, carers in NSW score approximately 20 percentage points lower on the Personal Wellbeing Index than the Australian average. A further one third (34%) had a long-term illness or disability that has been affected by their caring role, and 50% are experiencing high or very high psychological distress. Only 48% reported being satisfied with their own health.¹⁵ Further, when assisting care recipients to access public health services (defined as hospital and community health services), only 15% of carers reported that they were asked about their own needs, with the provision of information and carer support also registering as quite low (see Figure 1).

Figure 1: Carer inclusion and support by hospital and community health services¹⁶



While NSW Health continues to implement new measures to collect carer information, Carers NSW believes more can be done to proactively identify carer health needs and connect carers with the treatment they require. One way to encourage this is to mandate the inclusion of carers as a target group in local health district (LHD) Health Care Services Plans, which identify groups at higher risk than the remaining population of poor health. Another way of identifying carers' health needs that Carers NSW has previously advocated for is for a form of free carer health checks to be piloted in NSW, noting that such checks are routinely delivered in a range of settings in the UK, including in the home and at pharmacies, community care centres, sports centres and GP practices.

Evaluation data indicates that health checks led to sustained self-care and healthier behaviours for many carers. Carers reported that these checks are an opportunity to attend to their own health needs, and increase awareness of health issues and motivation to follow up with referrals for specialist treatment. Carers have also identified benefits to their psychological wellbeing and recognition of the demands of their caring role.¹⁷

As per our statements in previous Pre-Budget Submissions, Carers NSW recommends that carer health checks be piloted in one NSW LHD in the 2020-2021 Budget period to test suitability for state-wide delivery. Carers NSW believes that Community Health Nurses are best placed to conduct the health checks, working closely with other health professionals in order to identify carers through existing clients of services such as the LHD carer programs, Chronic Disease Management Program (CDMP), the Family and Carer Mental Health Program and the Grief and Loss Service. In addition to physical and psychological assessments, carer health checks would also provide an opportunity for Community Health Nurses to refer carers to existing carer supports and services, including those delivered under the Carer Gateway.

Carers NSW commends the inclusion of NDIS Hospital Liaison Officers and promotion of health lifestyle information and initiatives to carers in the 2020-22 Action Plan, but is concerned that neither initiative includes carer-focused, individualised information and support with regard to health and wellbeing.

Improved information and support at discharge

The NSW Carers Charter (the Charter) stipulates that carers are partners in care, and their choices, views and needs should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.¹⁸ The importance of carers is also recognised in the *NSW Mental Health Act 2007*. In Section 68, 'Principles for care and treatment', the Act stipulates that: (j) the role of carers for people with a mental illness or mental disorder and their rights under this Act to be kept informed, to be involved and to have information provided by them considered, should be given effect.¹⁹

In spite of these principles, many carers engaging with the health and mental health service systems in NSW experience inadequate information sharing by professionals and a lack of support on discharge, which increases risk to themselves and the person they care for. Carers NSW believes that patients should maintain their human right to privacy, but that where ongoing care is required to support a patient's wellbeing, this must be carefully balanced with a carer's right to receive information to assist them in their caring role.

Laura* was not informed by the treating team that her son, Max*, was discharged from a mental health facility, despite the fact it was expected that Max would live with Laura, and receive her support in recovery. Max was discharged to homelessness whilst still being unwell, and was subsequently reported missing for a period of time. The implications of this included a lack of psychosocial stability, limited access to mental health treatment and further negative effect on mental health outcomes.

*Names changed

Discharge is also a critical moment at which carers may be linked with carer-specific support, but carers and health professionals often report to Carers NSW that this is neglected due to lack of time and resources and lack of staff training and awareness. The rollout of Carer Gateway services across NSW and nationwide provides a more streamlined pathway to carer support and should be widely promoted throughout NSW Health services at the point of discharge, as well as during other relevant phases of admission and treatment.

The withholding of information from carers that has direct application to their caring role may negatively impact on the quality and sustainability of care provided, placing discharged patients at risk of complications or readmission. A lack of appropriate and ethical information sharing may also have a detrimental impact on care recipient outcomes, particularly with regards to physical and mental health, safety in the community, medication compliance, behaviour needs and potential relapse, and may even result in serious safeguarding risk. The current service environment relies on individuals and families maintaining their own care and support structures, but the effectiveness of these structures can be undermined by a lack of information and transparency and a lack of awareness that carers may need support in their own right.

Given the complexity in relation to information sharing, and the ethical implications of decision making with regards to privacy and confidentiality, there is an identified need for improved training and practical support for professionals to promote compliance under current legislation and ensure best outcomes for both consumer and carer.²⁰ Carers NSW encourages NSW Health to invest in consultation, policy development and improved discharge support to address this common situation.

Expand the provision of carer spaces in hospitals

The relatively limited carer-specific support that is visible to carers in public health settings is clear from Figure 1, however Carers NSW acknowledges that pockets of best practice and innovation exist within NSW that may not be reflected in these results. Family members and carers often provide critical informal support and assistance during a hospital stay. Carers can provide reassurance and support to the patient, facilitate communication with health professionals, support the delivery of optimal, person-centred health care, act as an advocate, monitor health care treatment and compliance, and may assist with practical tasks such as feeding and showering. The important role of carers in health service settings has been highlighted during visitor restrictions enacted in NSW and other states and territories during COVID-19, with some patients unable to receive the level of care required from health staff alone.

In an attempt to assess the need for carer-friendly spaces, Western Sydney LHD conducted a survey with Nurse Unit Managers across ten wards in a major metropolitan hospital. The survey found that between 2014 and 2015, an estimated 477 patients had a family member or carer stay overnight, with a total of 3070 overnight stays.²¹ Whilst some accompanied patients in single rooms, family members and carers often slept in chairs next to patients in shared rooms.²² The estimated average length of stay was four days, with the longest stay being over 30 days. This LHD found that having a family member or carer stay overnight benefits the patient, family member or carer and staff.

This evidence is consistent with reports to Carers NSW of the care provided to care recipients when in hospital. Hospital admissions may be one-off and a period of crisis for carers, or may be chronic with issues compounding as carers sacrifice their sleep and comfort to support their family member, partner or friend. Carers report that accommodation is prioritised within acute care settings; the chronicity of admissions should also be considered when establishing better accommodation for carers in hospital settings. Particular consideration should be given when a carer is travelling from a regional or rural and remote location, and in cases where a patient has become palliative. Designated carer spaces and flexible working hours remove unnecessary pressure from carers who are required to support their loved one in hospital. Cultural needs and expectations may further impact on the admission experiences of carers.

Carers NSW commends the inclusion of ‘carer zones’ in recent Bankstown and Westmead hospital developments and the implementation of a ‘gathering space’ for Aboriginal family members to collect as a group and discuss treatment and holistic care needs with the medical team. As other LHDs maintain and redevelop their buildings, Carers NSW recommends similar initiatives be scoped and implemented to meet the needs of local carers.

Address support gaps for carers of people with chronic and life limiting illness

In our two previous Pre-Budget Submissions, Carers NSW has urged the NSW Government to invest in increasing the physical infrastructure available for the delivery of respite services in NSW, noting that the NDIS, aged care system and new Carer Gateway funding models do not adequately provide for the construction and maintenance of these facilities, limiting overall stock.

Further, carers of people ineligible for planned respite under the NDIS and aged care systems, such as those with chronic illness, complex multiple health conditions and serious and life-limiting illness that is not yet at palliative stage, have limited and narrow options for accessing a structured break from the caring role. While the Carer Gateway can fund emergency respite and some planned respite for these groups, regular planned respite in a care facility is not intended to be a key part of the model. In addition, the appropriateness of a Carer Gateway respite referral relies on the existence of adequate local facilities for carers to use.

Carers NSW views this gap as an opportunity for the NSW Government to invest in additional respite infrastructure for carers of people within the health system who are not adequately supported by Commonwealth funded care programs.

Building on the residual, time limited disability and community care supports provided in-home by the NSW Health funded SASH and ComPacks programs, and the Queanbeyan respite facility funded in the 2019-20 State Budget, Carers NSW recommends that NSW Health look to pilot one to two new facilities built and staffed in partnership with local government funding and philanthropic investment. The Queanbeyan facility is one example of how this mixed model driven by community partnership can fill a service gap, and Carers NSW is aware of other examples in regional NSW where minimal NSW Government funding would achieve a similar outcome.

Recommendations

- Formally recognise carers’ own health needs in health service settings
- Pilot an individual carer health checks program
- Improve staff education and training regarding carer information and support at discharge
- Continue to expand the provision of carer-specific hospital spaces
- Pilot new respite infrastructure to enable carers of people with chronic and serious illness to take a break from the caring role

2. INCLUDE CARERS IN CRISIS RESPONSES

In the past 12 months, natural disasters and a public health crisis have posed significant threat to individuals and communities across Australia. The health, economic and social impacts of widespread drought, unprecedented bushfires and nationwide lockdown due to COVID-19 have affected all NSW residents, but have also resulted in unique and additional challenges for many carers. The next State

Budget period will be critical in addressing ongoing recovery from a challenging year and also poses an opportunity to improve safeguards for future, similar crises.

Improving outcomes for carers affected by natural disasters and health emergencies is twofold, involving both enhanced community, government and service responses and improved individual planning and responsiveness. This section deals primarily with how government, community and service responses can better address the needs of carers in present and future crises, while the following section examines individual preparedness.

Recognise the impacts on carers of recent emergencies

In NSW, the increasing frequency and intensity of extreme weather events including drought, bushfire, heatwaves, flooding and thunderstorms have posed practical challenges and considerable stress for many NSW residents, particularly for individuals living in regional, rural and remote areas, which have been most affected. For carers, the risks and challenges posed by these natural disasters are often exacerbated by the support needs of the person they are caring for.

Many people living with a disability or chronic health condition, or those who are ageing or frail, rely on regular support from family members and friends in preparing for and responding adequately to a natural disaster. Following the 2019-20 NSW bushfires, carers reported to Carers NSW issues in accessing health and emergency services and obtaining critical medication for the person they care for, potentially exacerbating their health and mental health issues at a time when these were already compromised. Carers have also reported facing significant challenges evacuating the person they care for to a safe and appropriate location as a result of shelters being unprepared to accommodate mobility and continence support needs or the use of life-saving equipment.

"I am edging towards burnout. I've had three days off since the fires happened excluding a few hours of respite a week, I am emotionally and physically exhausted."

- Carer of an ageing parent

In addition, Carers NSW has been closely monitoring COVID-19 developments in NSW, the ongoing government response and the wide ranging impacts the virus and associated physical distancing requirements have had on carers and the people they care for. Many carers provide care and support to people who are in higher risk categories, and many carers are in higher risk categories themselves due to age or an existing health condition. Restrictions on accessing services, moving about the community and public gatherings have also had significant impacts on carers' formal and informal support systems.²³

"The impact of coronavirus isolation had a huge impact on everyone in my household's mental health, but particularly my child with a disability. It will take him a long time to recover, and we are still feeling the stress and behavioural issues related to this."

- Respondent to the 2020 National Carer Survey

Evidence suggests that the psychological, economic and physical impacts of the pandemic on carers are, and will continue to be, significant.²⁴ Many carers have reported their struggle to balance study or paid work and caring, limited access to digital services, and increased financial costs of caring in conjunction with diminished employment security. In addition, carers have experienced an increase in their caring responsibilities with some services ceasing. Carers have been socially disconnected and their mental health and wellbeing, both immediately and in the long term, is at risk.

Carers NSW acknowledges the responsiveness of the NSW Government to emerging needs during this

unprecedented health and economic crisis, including regular and ongoing consultation with the disability sector via NSW Health's Disability Community of Practice, which has resulted in a number of

rapid improvements in policy and procedure as needs and circumstances in NSW have changed over time.

However, carers have highlighted confusing information and conflicting guidance from different levels of government throughout the crisis, which has exacerbated the challenges they are already experiencing in their own households and caring roles. Gaps in support, especially financial support, have also highlighted areas in which additional support may be offered by the NSW Government to facilitate societal and economic recovery and prepare the community and emergency services systems for a more effective response in future crises.

Even if by the new financial year COVID-19 cases and restrictions have eased considerably and no further major natural disasters have occurred, the economic, social and wellbeing impacts of the events of 2020 will persist. Carers NSW expects that the next State Budget will include measures to address ongoing economic recovery in NSW, and that improvements to health services and emergency services will be included, informed by learnings identified during this period of sustained crisis. Carers NSW therefore urges the NSW Government to ensure that vulnerable populations including carers are identified specifically in the State Budget, noting the considerable hardship many have experienced in relation to their financial security and physical and mental health.

Recommendations

- Include new and additional expenditure to support carers' financial wellbeing and physical and mental health, noting the ongoing impacts of recent natural disasters and COVID-19

Continue to include carers in crisis management

The natural disasters and public health crises experienced in recent months have highlighted a generally inadequate level of disaster preparedness within the broader community, which subsequently limits the timely and appropriate support available to people with disability or chronic health conditions, older people and their families and carers. The next section within the submission examines at the importance of individual contingency planning for these cohorts, including the ways in which contingency planning maximises preparedness and safety. However, Carers NSW advocates that planning at an individual level will only be successful in cases where emergency planning is strong at the community level and supports available are targeted and holistic.

Carers NSW has heard from many carers who report they have had limited supports available to them to meet their needs and the needs of the person they care for during both environmental and, more recently, public health crises. At times this has been due to a lack of sufficient information or publication of available support, while at other times it was due to a shortage in availability of the key supports required to ensure safety of the individual, carer and the broader family.

David* had to support his son Thomas* to evacuate when their family home was threatened by bushfires. Thomas has a diagnosis of Autism, which impacts his emotional regulation and behaviour. Their local evacuation centre was not able to accommodate Thomas' needs, jeopardising their safety as well as their access to suitable accommodation and support.

- Carer of a son living with Autism

Challenges during the NSW bushfires

Throughout the 2019-20 NSW bushfires, appropriate accommodation, access to assistive technology or life-saving equipment, as well as access to essential food or medication were identified by carers as being difficult to obtain, creating significant distress for both carers and the people they care for. In addition, carers who had planned and prepared for bushfire hazards were in some cases disadvantaged by community spaces and practices that did not accommodate the needs of the person they care for. Physically inaccessible venues and facilities and inclusive and flexible evacuation plans were identified as a particular issue. Change to routine and unfamiliar or unstructured environments can cause significant distress to some people living with dementia, intellectual disability or mental illness.

Challenges during the COVID-19 pandemic

During the COVID-19 pandemic, a lack of community preparedness has had significant implications for carers. These implications extend further and impact the psychosocial outcomes of those receiving care. Carers have reported diminished access to formal care services, carer support and respite care, subsequently impacting on carer health and wellbeing. In many cases, carers reported that some formal services had been reduced or ceased, leaving carers to fill service gaps without adequate training and irrespective of their capacity and willingness to supplement formal care. A lack of community preparedness and inclusion of carers in crisis management planning has meant that many carers are overwhelmed by increasing demand to perform multiple roles, often during a time of personal crisis.

“The loss of service during this pandemic has multiplied my issues struggles and problems as there has been no external supports or respite or space to recover in my own home plus becoming the sole emotional and social support for my loved one. My costs also skyrocketed specific to my caring role without any specific stimulus or support from the Government.”

- Respondent to the 2020 National Carer Survey

Inclusive emergency planning and response

While some resources and training exist to assist people with disability and older people to prepare for and respond in a crisis, these often neglect the critical role of family and friend carers in emergency situations, and rarely address the needs of these supporters themselves. Statistically, carers are likely to have disabilities and health conditions themselves,²⁵ and often incur significant financial and emotional costs in assisting their loved ones in an emergency situation.²⁶ Carers NSW strongly advocates for increased support and advice for carers on how to protect themselves, as well as the person they are caring for during a crisis, and how to recover physically, financially and emotionally during the recovery phase. Evidence based resources such as the Person-Centred Emergency Preparedness Toolkit²⁷ can support communities and services to incorporate inclusive emergency planning into their standard practice.

Carers NSW commends the NSW Government on their establishment of Resilience NSW, the lead disaster management agency for NSW, responsible for all aspects of disaster recovery and building community resilience to future disasters. As the leading actor in whole-of-government prevention, preparedness and

“The whole experience was extremely stressful and this was not helped by conflicting information from the Rural Fire Service, the police and the ambulance service. I appreciate that these organisations do excellent jobs in extremely stressful situations and it seems unfair to complain. I just would like some coordination and communication between them so that carers have a clear course of action for the people they love.”

- Carer of husband living with a disability

recovery effort, and will oversee and coordinate emergency management policy, service delivery and all aspects of disaster recovery, Carers NSW advocates that inclusion of people with disability, older people and carers be considered as a key priority, and is pleased to see that Resilience NSW has been consulting with local councils and community service organisations regarding outstanding resource and information needs. Carers NSW recommends that the development of new resources include carers, in the consultation and planning process, the content and the communications strategies.

While the new NSW Carers Strategy was predominantly developed based on consultation occurring prior to 2020, Carers NSW also recommends that the capacity to apply relevant initiatives in the first Action Plan to the emergency context be explored, including partnership with agencies at the frontlines of bushfire response and recovery and COVID-19 management.

Building emergency sector capacity

Resilience NSW and other agencies involved in coordinating emergency planning and response, including the Office for Emergency Management, Rural Fire Service, State Emergency Service (SES) and NSW Police, should be encouraged to consider their obligations as public sector agencies under the NSW *Carers (Recognition) Act 2010* (the Act) and ensure that carers are consulted on, and included in, all service planning and communications. Training in relation to the needs and experiences of people with disability, older people and carers in emergency situations should be provided to these first responders to ensure that adequate support and referral is provided in future crises.

Carers NSW is pleased to see that some disability focused preparedness initiatives have been undertaken, with the 'Get ready' online resources having a stream specifically directed at people with disability, and the Community Resilience Innovation Program funding community preparedness projects including one recent project raising awareness of the needs of adults with autism. Importantly, neither of these examples address carers as a specific audience or provide broad principles that could apply in any situation where a person is vulnerable due to disability, ageing or a health or mental health condition, especially where a carer has considerable involvement in supporting their day to day activities and decision making.

Carers NSW also notes that Community Resilience Innovation Program grants are currently listed as closed that funding limitations are noted. Additional funding to this important program will ensure that broader, more inclusive training and preparedness activities that are inclusive of people living with a broad range of conditions as well as their carers can be developed, in turn building the capacity of emergency services ahead of future bushfire seasons and other natural disasters.

Engaging local councils

Given their specific obligations under the NSW *Disability Inclusion Act 2014*, local councils also have an important role to play in identifying, contacting and supporting local residents who receive or provide care to ensure that they are safe in emergency situations. For example, some local councils have registers of people with disability and older people in the community that they periodically contact or conduct welfare checks with. Such lists could be maintained and used to support timely evacuation during natural disasters.

Local councils are also required to have accessible facilities that may be useful in emergency situations. Given the challenges some carers have reported in undertaking care tasks and maintaining the dignity of the person they care for at official shelters, local councils could identify accessible venues ahead of time that are set up specifically for those evacuating who have specific mobility and other support needs. Carers NSW urges all local councils, especially those particularly affected by the recent natural disasters and COVID-19 outbreaks, to revise their Disability Inclusion Action Plans in

light of their learnings from this period, to ensure that future emergency situations are managed more inclusively. Examples of best practice should also be identified and communicated state-wide.

Recommendations

- Improve emergency planning and evacuation procedures and infrastructure to ensure these are inclusive for carers, people living with disability and older people
- Embed a carer focus in existing resources and training surrounding crisis responses to support vulnerable groups
- Build the capacity of the emergency services sector to understand the support needs of carers and the people they care for
- Ensure that all agencies involved in emergency management consult and engage with carers in developing emergency plans
- Resource coordinated, localised emergency planning and response

Invest in targeted communication at times of crisis

Clear, consistent and tailored information and service responses that are explicitly carer-inclusive are critical to ensuring the safety of carers and the people they support. Throughout the recent natural disasters and for the duration of the COVID-19 pandemic, carers have reported either a complete lack of clear and tailored information, or that the information available is inconsistent and conflicted in nature. This has in turn undermined the physical and mental safety of carers, who have been inadvertently undermined in their capacity to provide care or enact emergency plans safely.

Information overload and mixed messages

During the COVID-19 pandemic, rapid policy change has made media commentary confusing, and information has quickly become out of date. Coordinated messaging regarding older people and people with disability has vastly improved since the start of the crisis, however in many cases information and resources applying recommendations and announcements to carers and the people they care for have been lacking. In particular, carers supporting a person at home have been confused about whether it is safe to continue to receive in-home aged care and disability services, whether they will be fined if they are seen in public with the person they care for, or whether they have to wear personal protective equipment (PPE) at home.

Throughout recent natural disaster events, such as the 2019-20 NSW bushfires, considerable information was made available through a number of platforms and news stations, allowing members of bushfire affected communities to make informed decisions about how they responded to the risks in their area. While there remained some confusion and inconsistency, NSW residents were better equipped than ever before. Carers have reported however, that there was limited guidance or support that was centred on their unique needs or the unique needs of their care recipient.

Without consistent and targeted information, many carers were unable to keep track of announcements that had a direct impact on their caring role, whether in terms of immediate emergency responses, or longer-term support packages that were announced to reduce the social and economic impacts of the bushfires. Peak bodies largely took on the unfunded role of interpreting and disseminating tailored information to these groups, as well as providing cohort-specific advice to government. Due to reduced and insecure funding in these sectors, this critical role may not be sustainable in future years.

Inclusive communication

Inequitable access to carer-inclusive resources and service responses has impacted different carer cohorts to varying degrees, influenced by factors including education and literacy, digital literacy, geographic location and cultural and linguistic diversity. Organisations who provide specific support to Aboriginal and Torres Strait Islander people reported that word-of-mouth information exchange is important within these communities, therefore services have focused on strategies to mobilise these channels.²⁸ Similarly, culturally and linguistically diverse communities are unique in the way they access and utilise information. A variety of cultural leaders reported that the translated COVID-19 resources provided by government were ‘nonsensical’²⁹ and Carers NSW heard that these communities were relying on their relatives living abroad to provide the latest government advice.

Many carers have been required to interpret and convey information to the people they care for during times of crisis where the information available has been inadequate. Aboriginal and Torres Strait Islander carers, culturally and linguistically diverse carers, as well as carers who are older or identify as LGBTIQ+ require targeted messaging and service response, in the form of translated resources, and culturally appropriate and sensitive service delivery and information delivered using a variety of mediums.

Evidence based preparation for future crises

While COVID-19 cases decrease in NSW, and ahead of the next devastating bushfire season, the NSW Government has the opportunity to invest in the development and testing of improved communication channels for future emergency information provision. Data from the apps and websites relied on by many NSW residents to track bushfire locations and obtain up to date information about COVID-19 restrictions can be analysed, and evaluative activities conducted, to ascertain how these technologies could be improved and built upon, especially in relation to reaching disadvantaged and hard to reach audiences.

Given the key role played by many peak bodies in informing, supporting and consulting with vulnerable groups including people with disability, older people and carers, these same groups and their member and stakeholder networks should be engaged in plans to improve the overall quality and inclusivity of emergency communication. Where additional resourcing is required to enable these organisations to participate, for example, through the Community Resilience Innovation Program funding mentioned earlier, then this should be budgeted for. Emergency reserve funding could also be explored to enable these organisations to produce timely, effective content for their respective audiences in future crises.

Recommendations

- Invest in evidence-based improvements in emergency communication technologies
- Engage with and resource community organisations to inform more inclusive emergency communication processes

Address gaps for carers in crisis response

As NSW has encountered a combination of severe natural disasters and one of the most catastrophic pandemics in human history, existing gaps and limitations in care services, emergency services and other service systems and infrastructure have become more apparent. In the current environment, the NSW government has an opportunity to identify ways in which service systems can be more secure and responsive when future challenges arise.

"[We] are noticing fault lines in structures that are in place for carers. These are shockingly inadequate"

- Carer researcher

Emergency transport

Carers affected by bushfire have highlighted the difficulty of transporting a person with disability or frail older person in the case of evacuation, especially where this has not been able to occur ahead of time. Emergency service vehicles should, where possible, be made accessible so that they can transport vulnerable individuals in an emergency situation. While NSW Ambulance services and accessible taxis are sometimes engaged for these services, when roads are blocked or demand is high, they may not be available.

Energy and communications infrastructure

During a natural disaster, a number of essential services can be cut off, including power sources that may be relied upon for life saving equipment or medication, and mobile reception. While in some cases this damage is difficult to predict or reverse during a crisis, planning should be in place to ensure that networks and infrastructure are as stable as possible, with contingency planning undertaken. Messaging to members of the public regarding how to plan for occasions when these services are not available should also be explored so that communities are better prepared when breakdowns occur.

The care workforce

With home-care, residential care and health care workers unable, or unwilling, to attend work during the NSW bushfire crisis and COVID-19 pandemic, many people requiring care, and subsequently many carers, were left without critical support, in some cases resulting in significant risk of harm. While it is important that employers act with caution to protect their workers and clients in these situations, it is also important that emergency plans are in place so that vulnerable individuals and families are not left in unsafe conditions. Should workers be withdrawn, emergency rosters could be enacted, or at minimum, remote contact made and emergency services informed to ensure that vulnerable individuals are checked in on periodically.

Accessible public venues

While State and local governments in NSW have clear obligations to ensure that public facilities are accessible and inclusive, many continue to be inaccessible to people with disability and those who are frail due to ageing. This became apparent during evacuations in response to the NSW bushfires, when some carers found identified evacuation centres unable to meet the needs of the person they care for. It is important that the types of facilities relied upon for this purpose be audited for accessibility so that they are appropriate and inclusive for all uses, including emergency evacuation.

Care provision while in hospital or residential aged care

Visitor restrictions applied to hospitals and aged care facilities during COVID-19 highlighted just how much ongoing care and support patients and residents receive from family members and friends. The significant distress caused to many carers and care recipients during these restrictions often related not only to the suspension of face to face emotional and social support, but also to carers' inability to provide critical practical care and support that staff were simply not skilled or resourced to provide.

It is important that health care and aged care facilities examine the 'hidden labour' being undertaken by carers to ensure that this support can be continued when crises occur, and also to resource staff to provide equivalent support during admission to reduce the pressure on carers, who may not be in a position to sustainably provide this care while the person is not at home. Travel and parking expenses, as well as time off work and away from family responsibilities, may be untenable for carers whose care is still required when their loved one is in hospital or in a residential aged care facility.

Carers NSW recommends that the NSW Government conduct a comprehensive review, in consultation with people with disability, older people and carers, and the organisations that support them, to identify services and infrastructure that need to be improved in order to mitigate preventable shortfalls during future crisis situations.

Recommendations

- Review and address shortfalls in emergency transport, energy and communications infrastructure, the paid care workforce, accessible public venues and the provision of care in residential facilities

3. SUPPORT CARERS TO PLAN AND PREPARE

The importance of carers planning ahead was highlighted in the last section in relation to crisis events affecting the whole community. However, planning is just as important for individual crisis events, such as sudden changes in the caring role, and for more incremental or expected changes, such as the transition from one primary carer to another. While individuals can be encouraged and supported to plan with effective information and resources, not all feel confident to do so alone, and many require more personally tailored information and support in order to be prepared for changes and other challenges in their caring role.

This section examines opportunities for the NSW Government to build carers' capacity and resilience in navigating the challenges of caring, ensuring that caring is both safe and sustainable.

Invest in holistic service navigation support

As emphasised in previous Carers NSW Pre-Budget Submissions, many carers experience significant barriers in accessing and navigating services with or on behalf of the person they care for. Carers and service providers report to Carers NSW that issues relating to the access and navigation of services are particularly prevalent in the context of disability and aged care services. Large numbers of NSW respondents to the 2020 National Carer Survey indicated that organising aged care and disability services was difficult, with the most common challenges being waiting times, difficulty accessing information and the time and energy required to organise services.³⁰

However, carers usually navigate multiple specialist and mainstream service systems at the same time, often spending considerable time doing so, and centralised information and assistance is very

limited, with most being focused in online resources that can be inaccessible for some carers, and are often out of date or hard to find. Many of the service systems they navigate are State funded, such as hospital and community health services, mental health services, which carers in NSW also reported in the 2020 National Carer Survey to be challenging to navigate, with minimal information provision, support and inclusion provided.³¹

Service navigation for carers is, therefore, more than a Federal issue to be addressed in relation to the Federally funded disability, aged care and carer support service systems, and Carers NSW believes that the NSW Government has a role in supporting carers with this complexity, especially since it previously funded types of support that assisted with service navigation, such as case management for people with disability and their families and Ability Links NSW. Carers NSW welcomes the new service navigation support for carers through the Service NSW website and some Service NSW centres as an important starting point in centralising the service information available to carers.

Navigating services with or on behalf of a person with disability

In the context of the NDIS, many people with disability and their carers are still adjusting to a new service system that changes constantly and about which there remains limited clear, public information. Support types that encompass a service coordination role, like case management and advocacy, have also been eroded in the NDIS transition, with limited individual navigation support on offer from local area coordinators (LACs) and support coordinators, when funded. Indeed, Carers NSW has previously found that the administrative work undertaken by carers went up with the implementation of the NDIS.³²

In addition, people with disability and their carers are concurrently attempting to navigate other mainstream services that are equally complex but less inclusive of people with disability, such as health, education, justice and accommodation services, with a very fragmented and under-resourced advocacy sector to support them when challenges arise. Carers NSW acknowledges that the Commonwealth Government has made a commitment to funding the NDAP, NDIS Appeal Support program and Disability Representative Organisations, however, many of the service systems in which people with disability and their carers need assistance with advocacy fall within the remit of the State Government.

In a complex service environment with ongoing change and jurisdictional complexity, the funding shortfall for disability advocacy will continue to grow with the reduction of NSW Government funding to the disability advocacy sector. And yet, there remains strong Federal emphasis on the importance of continued funding for advocacy at state and territory level.³³

Navigating services with or on behalf of an older person

For older Australians, their families and carers, the siloed nature of health and aged care systems present their own set of issues, particularly around the continuum of care and its coordination. While advocacy services are more centralised and securely resourced than in the disability sector, in the form of the Older Persons Advocacy Network, many carers struggle to engage effectively with My Aged Care, and the provision of information and service navigation support has been minimally funded, leaving many older people to rely on carers putting in many hours of research and phoning around in order to access adequate support.

Additionally, lack of information about service costs and quality has placed additional strain on carers who are trying to source safe, reliable and affordable services for their care recipient. For people who are ageing and frail who are also interacting with the health system, the provision of adequate care coordination is vital to the effective use of dual service systems and minimisation of service gaps.

While the Commonwealth Government has attempted to support older people, their families and carers navigate the aged care system through COTA's Aged Care Navigator Trial, this initiative has so far been volunteer based and geographically limited, meaning that it is not available to all older people and their carers across NSW.

Given the NSW Government's commitment to respond to the opportunities and challenges of our ageing population by renewing the NSW Ageing Strategy, Carers NSW believes this is the opportunity to fund State-based aged care support services that allow older or ageing Australians and their carers to plan and coordinate aged care services confidently.

Carers NSW would like to highlight the role of the NSW Government in the ongoing provision of disability advocacy at both individual and systemic levels and encourage further investigation of the unmet need for disability advocacy in Australia. Ongoing and increased investment in disability advocacy will ensure that all people with disability have fair and equitable access to services and supports and can be supported against potential injustices, whilst reducing strain on carers who would otherwise be required to fill this advocacy gap.

Navigating health and mental health services

Carers often report to Carers NSW feeling confused and exhausted in trying to understand what service options are available to the people they care for in the health and mental health service systems, especially as information to support the caring role is not always provided.³⁴ The complexities of navigating the complaints and appeals pathways associated with these systems, as well as the aged care and disability service systems discussed earlier, prevent many carers from seeking improved support, and in some cases from obtaining a satisfactory outcome in spite of taking the issue further.

Investing in innovation

Carers NSW commends the NSW Government's investment in innovative health justice partnerships through LegalAid NSW and notes the potential of such partnerships to effectively leverage a combination of public, private and not-for-profit resources and expertise in providing individualised, face to face support to people navigating systems with complex interfaces and right frameworks. Carers NSW urges the NSW Government to consider how these models may be applied in the context of service navigation within and outside the health system to benefit people requiring ongoing care and their carers.

Carers NSW also commends the NSW Government's commitment to providing increased, carer-specific support and information through Service NSW outlets and the Service NSW website, as noted in the new Carers Strategy's first Action Plan for 2020-22. However, it is important to note that carers' engagement with services is not limited to State funded services, nor is it limited to either specialist care or mainstream services. As such, any intermediary support to assist carers to access services and entitlements must be inclusive of information and referrals across State departments and agencies and across all levels of government.

In addition, in the context of eroded disability advocacy funding at state level, and ongoing resourcing of a range of smaller, targeted legal and mediation services through LegalAid NSW and the Seniors Rights Service, Carers NSW urges the NSW Government to consider centralising and expanding these funds to create new individual advocacy positions with legal training that are designed to assist any person with disability, older person or person with a health condition *and* their carers to navigate service systems and resolve any issues that arise. These roles could sit within an existing agency, such as LegalAid NSW or Service NSW, or could be tendered to peak bodies with experience providing individual advocacy support.

Recommendations

- Support innovative partnership approaches to inform carers of their rights and service options
- Centralise and expand existing legal and advocacy funding to be available to all carers and the people they care for

Support carers to plan for the future

Caring roles are as diverse as carers themselves, and are subject to change over time, as the person with care needs ages or their condition progresses, and as external factors such as service system changes affect the support available. Changes in the carer's health and wellbeing or availability due to life commitments such as employment can also impact the sustainability and form of the caring role. Key changes that carers report to Carers NSW as challenging to navigate are the transition of an older person into residential aged care, the progression through palliative care and transition to being a former carer, the succession of the primary carer role within a family due to ageing, and the sudden changes that can occur due to an unanticipated health crisis for the person being cared for or the carer themselves.

Supports and services exist to assist each of these groups with managing the challenges of changes, and some resources exist to support planning and preparation. However, these supports and resources are often not known about, provided to carers, adequately resourced or available when needed. This section examines three of the highest priority areas identified by Carers NSW as needing additional investment from the NSW Government.

Succession planning

Many carers have conveyed to Carers NSW their concerns about how the person they care for will be supported in the future when they are no longer able to provide care themselves. Planning for the future can be extremely difficult and stressful for both the carer and the person they care for, particularly as these processes are often complex, with limited formalised support available to guide carers as they make important decisions.

Carers NSW recognises that future planning is relevant for most, if not all carers, and believes that targeted, carer-specific supports should be available to assist carers plan for the future. Carers NSW would like note however, that there are specific cohorts of carers who may require more tailored assistance. Older parent carers and adult sibling carers have been identified by Carers NSW as two carer cohorts who may experience particular barriers to planning and implementing care arrangements for the future.

ABS data indicates that nearly one in three older carers provide more than 60 hours of care per week, and 40% of older carers reporting they have been in a caring role for more than 10 years.³⁵ Older carers are often less engaged with formalised services and many are often socially isolated. Long-term caring roles, lack of familiarity with formalised service systems and the small social network many carers engage in can create a number of barriers to starting the process of future planning. It is also important to recognise that many of these barriers are exacerbated if older carers are from culturally and linguistically diverse backgrounds.

For adult sibling carers, challenges may arise that relate to their level of preparedness to begin a primary care role in place of their parent. While many adult siblings have investigated mechanisms to support their sibling when they are no longer around, they often note the complexity of such services. In particular, adult siblings report the lack of suitable housing options as well as difficulties ensuring the ongoing financial security of their sibling. For others, while they recognise a need to put in place

support mechanisms for the future, this can often be difficult due to the immediate demands of their caring role while also balancing other aspects of their own lives.

Carers NSW has a long history of supporting carers plan for the future. The Older Parent Carer Program, which was delivered for over ten years, centred on building the capacity of ageing parent carers to confidently plan for a time when they are no longer able to care. While the delivery of this program has since ceased, Carers NSW strongly believes that the need for a carer-specific future planning support service still exists, particularly as future planning is becoming increasingly linked with supported decision-making. The Carer Gateway and associated NDIS funded National Community Connector Program for ageing parent carers provides some assistance with putting in place formal care supports, however there are many legally and relationally complex elements of planning for the future that are outside the scope of this program, some of which require specialist advice and may be costly.

Carers NSW therefore recommends that the NSW Government consider investing in new programs that support carers to undertake the legal, financial and relational planning associated with sustainable succession of care into the future, to ensure carers and the person they care for are supported to make decisions that adequately meet the needs of the entire family.

Emergency planning

Future planning is not limited to making arrangements for a time when the carer is no longer caring for their family member or friend, but also involves preparing for emergencies where the carer is suddenly unable to care for a short period of time. As identified earlier in this submission, the series of natural disasters experienced recently in NSW and the COVID-19 pandemic have highlighted that many carers do not have plans in place that can be easily enacted if an emergency inhibits their ability to care.

Carers NSW commends the provision of emergency respite care and a downloadable Emergency Plan under the Carer Gateway and is working on additional initiatives within our Carer Gateway service delivery area of NSW 4 to enhance carers' access to emergency planning resources. However, with awareness and use of the Carer Gateway still relatively new due to its recent commencement and the challenges of reaching carers during COVID-19, Carers NSW believes that the NSW Government should have a role in proactively supporting carers to plan for emergencies, especially as they relate to natural disasters, as noted previously.

Adapting and expanding existing individual-focused 'Get ready' resources could be one simple way of addressing this need. However, it should also be noted that emergencies are often personal, rather than community-wide, in nature, and support and resources should reflect this.

Planning with, or for, someone with a cognitive impairment

Future planning is also closely linked to supported decision making in cases where carers are supporting a family member or friend with a condition that involves cognitive impairment, such as intellectual disability, dementia or severe mental illness. The spectrum of decision making, from independent, to supported decision making, to substitute decision making, is complex and fluid. Capacity and decision making has recently been at the centre of discussion for both older Australians and people with disability, their families and carers, especially in the context of neglect and abuse. Despite this, consistent guidelines supporting these practices are yet to be provided, reducing the capacity of carers and others to facilitate the self-determination of older people or people with disability in relation to decisions that affect their everyday lives.

Many carers report regularly providing decision making support to the person for whom they care. Decisions can vary in complexity, from more simple daily decisions such as food and nutritional choices, through to complex decisions relating to finances, accommodation or support. Person

centred and human rights approaches rightly situate substitute decision making as a last resort. Carers NSW advocates that the informal decision-making support of carers can mitigate the requirement for substitute decision making. Where carers provide information, emotional support, or support with reading and writing, the decision-making autonomy of people with disability is maximised.

Carers NSW recently delivered a webinar session on supported decision making in partnership with Relationships Australia NSW and the Office of Public Guardian, giving carers and service providers an introduction to supported decision making. Based on the overwhelmingly positive feedback, Carers NSW recommends that the NSW Government funds the development of supported decision making resources that builds the capacity of carers to understand how they can support the person they care for to make decisions on their own behalf.

Carers NSW commends the ongoing work of the Public Guardian and Relationships Australia NSW in increasing awareness and understanding among carers, people with disability and service providers of the importance of supported decision making, and urges the NSW Government to resource additional capacity building and partnership opportunities in this important area.

Carers NSW also notes the work of Macquarie University's Health Science Centre and the establishment of the Capacity and Capability Clinic, which supports the autonomy of individuals faced with complex health, welfare, legal or financial decisions by providing medico-legal assessments. While such an initiative looks to support families and carers to make decisions that facilitate the autonomy and independence of older people, Carers NSW notes that such consultations and supports are not free or subsidised, making it difficult for many carers to access this service. Carers NSW recommends that the NSW Government invests in a similar program or service which carers can access at a subsidised cost.

Recommendations

- Fund targeted support to assist carers with succession and emergency planning
- Provide additional subsidised access to specialist advice regarding capacity and future planning

Equip carers with the skills to care safely and sustainably

Deloitte Access Economics estimates that the value of informal care provided by family and friend carers has risen to \$72 billion each year,³ and projects that it would cost the Australian Government just under \$1.5 billion per week to replace. ABS data indicates that many carers are closely involved in the care and support of their family member or friend, with roughly 80% of primary carers residing in the same house as their care recipient, most of whom identified they assisted or supervised with mobility tasks, self-care and communication. Despite their significant contribution to care in the community, most carers receive no formal training or support in how to deliver care safely and correctly.

Give carers confidence to care well

Carers have expressed to Carers NSW their desire for services and supports that give them useful and practical guidance on how to provide care that is safe and sustainable for themselves and the person they care for. Data from consecutive Carers NSW Carer Surveys has highlighted how carer

³ Carers NSW estimate based on Deloitte Access Economics (2020) *the economic value of informal care in Australia in 2020*, Carers Australia.

wellbeing is closely linked to the sustainability of care they provide, demonstrating that carers with highly intensive and complex caring roles may experience higher levels of distress without appropriate and timely support. It is therefore crucial that carers are given opportunities that allow them to build capacity and develop critical skills to ensure they feel confident providing care to their family member or friend.

Carers NSW has raised concerns on a number of occasions about the adequacy of practical support carers receive to ensure care is both safe and sustainable for the carer and care recipient. Carers NSW recognises the role of Carer Gateway services, which provide tailored support that facilitates long-lasting care relationships that do not negatively impact on the carer. While these services are rightly focused on supporting carer's wellbeing through various domains, there is limited support available for carers to build practical skills that support in their caring role.

Build on evidence-based existing models

Carers NSW has continued to look for opportunities to build carer capacity in the context of practical skills development and has recently developed a series of education and training modules that focus on upskilling carers to care safely and sustainably for an older person at home or in the community. The Consumer and Carer Coaching Program (3CP), funded through the Commonwealth Home Support Programme's (CHSP) Innovation Fund, has been developed in consultation with carers to support their navigation of increasing care needs. Through the 3CP, carers can enhance their ability to provide care to their family member or friend, and be provided with a skillset that may be transferable to paid care work, where this is of interest, and potentially addressing current shortages in the aged care workforce.

Carers NSW believes that the 3CP project is adaptable to other caring contexts and may be particularly beneficial in supporting carers to identify and understand their rights as well as develop practical skills. As previously mentioned in this submission, discharge in health and mental health settings continues to be an issue for many carers, as they are not always notified when the person they care for has been discharged. Carers NSW believes that future iterations of the 3CP project could intersect with the new Carers Strategy, which Carers NSW is pleased to observe has a strong carer rights focus, to develop capacity building resources.

As such, Carers NSW recommends that the NSW Government invests in the adaptation of the current 3CP project to support carers in various caring roles. Carers NSW also recommends that the NSW Government invest in the piloting of the carer coaching component of the existing 3CP project to demonstrate the utility and benefits of carer coaching.

Recommendations

- Support the expansion and application of practical carer skills training and mentoring in a range of caring contexts

Invest in carers' digital access and literacy

The COVID-19 pandemic has highlighted a number of significant service gaps for carers and the person they care for, particularly in the context of digital access and literacy. Sudden reliance on technology, including for social connection, medical appointments, therapies and other care responsibilities has presented considerable challenges for carers, particularly as their ability to access technology as well as their capacity to use it effectively varies widely.

Carers NSW commends the NSW Government on their commitment to support older Australians build their capacity in terms of digital literacy while meeting needs relating to social connection, through

ongoing programs such as Tech Savvy Seniors and through new funding allocated during the pandemic to improve social connectedness and digital capacity. The considerable demand for these grants indicates that there may be substantial need and capacity in this area that should receive additional resourcing beyond the present COVID-19 crisis.

Facilitate equitable access to telehealth

The 2020 National Carer Survey found that most carers in NSW were fairly confident using the internet to find information, use services and stay in contact with friends and family. However, only a few were taking advantage of online groups, forums and online training, which are offered by Carer Gateway, Carers NSW and other State and Federally funded organisations. While many carers have benefited from the rapid digitisation of essential services through the increase in Telehealth during the pandemic, some carers have also indicated that there has been limited training and assistance available to use such services, also noting that for some people with cognitive impairment, telehealth does not always meet their needs. Without sufficient training and support to confidently use and navigate digital services more broadly, carers are at risk of becoming increasingly socially isolated while also supplementing the care that would otherwise be provided through telehealth services.

Digital inclusion is becoming an increasing issue during COVID-19, especially for older carers, young carers and those based regionally and remotely. Consultations conducted during the pandemic by Carers NSW³⁶ indicated that common barriers to accessing digital services and support included: the cost of devices, low digital literacy and the complexity and variation of websites and applications. These barriers have caused some carers to disengage from needed services, increasing their isolation during an already challenging period, and waiting indefinitely for face to face services to re-open.

Challenges during COVID-19

For older carers, particularly those in long-term caring roles, a significant amount of their social connection is derived through face-to-face contact, as many do not have the confidence or resources to effectively navigate online supports. This poses a considerable challenge in a service system that is increasingly shifting towards online delivery. Similarly, carers who are based in regional and remote communities have indicated the high level of difficulty in accessing online services, as the adequate infrastructure simply does not exist to facilitate their engagement. For young carers, access to digital services may be impacted by their ability to use such supports privately, particularly if they are engaging in peer support activities, where they may be unable to share their experiences as a young carer if they are in close proximity to the person they care for.

Social distancing measures implemented during the COVID-19 pandemic have only served to exacerbate these challenges. Many carers have been separated from the person they care for as well as their own informal support networks. At times this has been due to increased health risks for one or both parties, at other times it has been the result of service and community lock downs. Older carers and the vulnerable cohorts for whom they care tend to be over represented in groups known to have low digital inclusion, meaning that a transition to online models of connection during COVID-19 has carried additional challenges. Young carers, particularly those based regionally or remotely may also be facing barriers to education, as some have identified there are not enough devices to complete their schoolwork online.

More than digital literacy

Many technology-based programs are designed for older Australians and focus on digital skills and literacy. While this is important, where there has been less support is in addressing the other barriers to digital access, especially those relating to the cost and quality of devices and internet connections. During and beyond COVID-19, the NSW Government has an opportunity to expand the reach and

uptake of digitised services by upskilling carers that experience a range of barriers to digital engagement.

Recommendations

- Provide additional digital access support outside of ageing populations
- Address digital access barriers related to factors such as affordability

4. IMPROVE CARERS' FINANCIAL SECURITY

Carers often face significant financial pressure as a result of their caring role due to increased costs associated with care or reduced income due to the impact of caring on their education and employment. At consultations for the new NSW Carers Strategy: *Caring in NSW 2020 – 2030* (the Strategy), financial hardship and the associated need for increased financial assistance were among the most commonly raised themes. Carers NSW commends the NSW Government for identifying the improvement of carer financial wellbeing and economic opportunities as a priority in the recently released Strategy and the commitment to a range of projects and initiatives associated with carer financial wellbeing and economic opportunities in the Action Plan 2020-2022.³⁷

In 2018, the median gross income of all carers was approximately \$200 per week less than non-carers and approximately half of primary carers lived in a household in the lowest two quintiles, twice that of non-carers.³⁸ The recently conducted 2020 National Carer Survey³⁹ found that more than half of NSW respondents experienced at least one form of financial stress in their household in the year prior to completing the Survey, compared to just over one in five Australian households. A total of 14% of NSW respondents experienced more than 4 instances of financial stress in their household – and were therefore considered to be in financial distress – in the prior 12 months. The NCOSS Cost of Living Survey 2019⁴⁰ also found that in a random sample of persons living in low and lower to middle income household, carers were significantly overrepresented.

“Recognise that many carers have not had the ability to work and accrue superannuation or savings”

- Respondent to 2020 Pre-Budget Submission Stakeholder Feedback Form

Financial impacts of caring

One potential contributing factor to carers' financial stress is their high rate of expenditure on the costs of care. The 2020 National Carer Survey found that almost two thirds of carers reported contributing financially to the costs of medicine for the person they cared for, with half contributing to their transport costs. Just over one in five carers did not incur any additional costs relating to their caring role.⁴¹

While caring can make it difficult for carers to meet their daily living costs, caring can also impact on the financial security of carers over the lifespan. The 2020 National Carer Survey also found that caring can have an impact on the career trajectory of carers in NSW, with one in four respondents (25%) reporting that they have reduced their hours of work to care, just over one in five (22%) reporting that they have quit work or looking to work to care and 14% reporting that they had taken a job lower than their skill set.⁴² Anecdotal evidence collected through Carers NSW service provision and consultation further indicates that many carers have little superannuation in which to plan for their later life and needs.

With reduced income and increased costs, many carers are not in a position to receive or contribute to their superannuation. For many carers, retirement and superannuation outcomes are not determined by factors such as financial capacity or literacy, but rather by the inability to accrue a retirement income that will be sustainable and adequate for later life.

Additional challenges during COVID-19

Carers NSW has heard in their consultation with carers and stakeholders during COVID-19⁴³ and in national and international research⁴⁴ that recent crises have placed even greater financial strain on carers with many experiencing additional costs such as PPE or home delivery costs and disruption to their employment as a direct result of crises or an increased caring role during the crises. This financial strain has been further exacerbated by compounding crises with NSW experiencing bushfires, floods, droughts and the coronavirus pandemic, with no reprieve in 2020.

Beyond financial literacy

Carers NSW believes that carers require a continuum of support with finances, from education about consumer and financial rights, to carer-aware financial counselling, and in some cases additional financial support from Government, where costs associated with caring are not covered under pre-existing schemes. Carers NSW therefore welcomes the focus on carer finances in the Action Plan, and look forward to working with the NSW Government in improving carers' financial literacy. However, Carers NSW wishes to stress that carers often point out that it is not only financial literacy that prevents them from having financial security. Sometimes, there are simply not adequate financial resources to cover their costs and needs. Carers NSW therefore urges the NSW Government to ensure that, wherever possible, measures are taken to reduce financial pressure on carers, especially in the wake of the COVID-19 pandemic.

Simplify access to available financial supports for carers

Carers NSW commends the NSW Government on their numerous initiatives to address issues related to cost of living for people in NSW, and more recently to centralise these opportunities through Service NSW. While many carers are likely to benefit from the range of schemes and rebates available, carers are currently required to identify and determine which rebates and schemes they may be eligible for and apply for each individually. For carers, who are often time poor and already navigating complex service systems with or on behalf of those they care for, identifying schemes and rebates and then completing each individual application, inadvertently prevents carers from accessing these supports.

“Ensure all carers are aware of every service or benefit available to them.”

- Carers NSW 2020 PBS Stakeholder Survey

Cost of living supports

Carers NSW commends the introduction of Cost of Living experts to assist with identifying and navigating existing rebate schemes and recent commitment to supporting carers to access cost of living supports as outlined in the NSW Carers Strategy Action Plan.⁴⁵ These commitments will likely increase carer awareness both within Service NSW and in the community and enable carers to identify a range of schemes and rebates that will enable them to optimise their savings, as well as support them to access other carer supports within the community.

Carers NSW believes that building on the current initiatives to improve carer awareness of schemes and rebates, further investment by the NSW Government should be aimed at improving the accessibility of schemes and rebates. Currently, where carers are eligible for schemes and rebates

that address costs of living, carers are required to complete multiple applications, with separate applications for most schemes or rebates.

Carers NSW believes that Service NSW should improve the accessibility of available schemes and rebates through investment in the simplification of application process and digital infrastructure, creating a streamlined single application for all rebates and schemes that are available. Reducing the number of applications will enable carers, who are often time poor and already navigating multiple systems to access a greater number and range of available savings opportunities and improve their ability to meet their costs of living.

Expanding scope

Carers NSW also believes that the NSW Government should continue to expand existing schemes and rebates and explore further opportunities to address other costs of living, especially those that have been highlighted or exacerbated during COVID-19, such as telecommunication costs and the costs of digital devices, especially where they are needed for educational purposes. It should also be noted that currently, carers receiving Carer Payment or Carer Allowance are not eligible for the Commonwealth Government's Telephone Allowance,⁴⁶ which is available to recipients of the Jobseeker Payment, Youth Allowance and Parenting Payment and is assisting many with additional communications costs accrued during COVID-19.

During, and prior to, the COVID-19 pandemic, many carers are reliant on the internet to access education and employment, as well as carer support services, health services and social support as formal and informal supports move increasingly online. However, Carers NSW has heard from many carers, that the additional costs associated with purchasing digital devices and connecting to or increasing their network capacity during COVID-19 has placed further strain on their finances.⁴⁷ Carers NSW recommends that the NSW Government explore and invest in schemes and rebates to support carers to access online services and supports that assist in the maintenance and improvement of their health and wellbeing and enable them to participate as members of the community.

Recommendations

- Invest in IT infrastructure to create a single-touch application for all NSW Government schemes and rebates that address costs of living
- Explore opportunities and expand schemes and rebates to identify and address the unmet costs of caring in NSW

Include carers in schemes and rebates

For many older carers and carers of older people, travel costs represent a significant proportion of the expenses involved in caring for someone. The 2020 National Carer Survey found that approximately half of all NSW respondents contributed to the transport costs for the person that they were caring for. Carers also commonly incur additional costs associated with modifying a vehicle and parking in order to access services such as hospitals.

While the NSW Government has invested in a number of schemes and programs that seek to offset the costs of public transport, such as the Community Transport Program (CTP), carers registration refund, Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) and hospital parking concession rates, many older carers and carers of older people report experiencing difficulty accessing these services. Additionally, Carers NSW has concerns that aged-specific services or

initiatives that have the potential to facilitate greater connection and support for older carers, are not necessarily carer inclusive.

Carers NSW has previously expressed concerns about the roll out of the Regional Seniors Travel Card trial to Transport for NSW, noting that a number of regional and rural carers of pension age living in NSW, have been excluded from the trial as the result of receiving the Carer Payment, rather than the Age Pension. While Carers NSW understands that this scheme is still in trial phase, Carers NSW believes that the exclusion of carers of pension age – even when they are receiving the Carer Payment, an equivalent pension – is both unequitable and inconsistent with the NSW Government's obligations under the *NSW Carers (Recognition) Act 2010*.

Carers NSW recommends that the NSW Government extends the Regional Seniors Travel Card to carers of pension age who may be receiving alternate government pensions, including the Carer Payment. Furthermore, Carers NSW recommends that the NSW Government ensure that future cost saving schemes consider and include carers of pension age who may be receiving alternate Government pensions (i.e. Carer Payment, Disability Support Pension).

Recommendations

- Expand transport subsidies and rebates to explicitly include carers

CONCLUSION

This Pre-Budget Submission has highlighted opportunities 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 new *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. The 35 recommendations identified throughout this submission are listed below:

Continue to champion carer recognition

- Provide continued funding for new and existing innovative projects supporting carers in NSW
- Adequately resource the Strategy to enable broad, creative promotion to maximise awareness
- Complement and build on other relevant strategies and frameworks
- Embed a strong, independent and transparent evaluation plan in the delivery of the Strategy
- Improve oversight and visibility of the Strategy by naming a Minister for Carers
- Capture and widely promote best practice initiatives in carer recognition within the public sector
- Communicate progress against the Act and Strategy to carers in plain language on a more regular basis
- Monitor and respond to gaps in carer support to ensure carers feel recognised and supported
- Work to strengthen carer rights and streamline complaints processes to better support carers
- Raise public awareness of the legislated definition of carers to reduce confusion over, and misuse of, the term
- Monitor and correct inconsistent usage of carer language within the NSW Government
- Formally recognise carers' own health needs in health service settings

- Pilot an individual carer health checks program
- Improve staff education and training regarding carer information and support at discharge
- Continue to expand the provision of carer-specific hospital spaces
- Pilot new respite infrastructure to enable carers of people with chronic and serious illness to take a break from the caring role

Include carers in crisis responses

- Include new and additional expenditure to support carers' financial wellbeing and physical and mental health, noting the ongoing impacts of recent natural disasters and COVID-19
- Improve emergency planning and evacuation procedures and infrastructure to ensure these are inclusive for carers, people living with disability and older people
- Embed a carer focus in existing resources and training surrounding crisis responses to support vulnerable groups
- Build the capacity of the emergency services sector to understand the support needs of carers and the people they care for
- Ensure that all agencies involved in emergency management consult and engage with carers in developing emergency plans
- Resource coordinated, localised emergency planning and response
- Invest in evidence-based improvements in emergency communication technologies
- Engage with and resource community organisations to inform more inclusive emergency communication processes
- Review and address shortfalls in emergency transport, energy and communications infrastructure, the care workforce, accessible public venues and the provision of care in residential facilities

Support carers to plan and prepare

- Support innovative partnership approaches to inform carers of their rights and service options
- Centralise and expand existing legal and advocacy funding to be available to all carers and the people they care for
- Fund targeted support to assist carers with succession and emergency planning
- Provide additional subsidised access to specialist advice regarding capacity and future planning
- Support the expansion and application of practical carer skills training and mentoring in a range of caring contexts
- Provide additional digital access support outside of ageing populations
- Address digital access barriers related to factors such as affordability

Improve carers' financial security

- Invest in IT infrastructure to create a single-touch application for all NSW Government schemes and rebates that address costs of living
- Explore opportunities and expand schemes and rebates to identify and address the unmet costs of caring in NSW
- Expand transport subsidies and rebates to explicitly include carers

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