



**A fresh start:
Reimagining support for carers
Carers NSW Pre-Budget Submission 2024-25**

ABOUT CARERS NSW

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

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

www.carersnsw.org.au

<https://twitter.com/CarersNSW>

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

ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

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

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November 2023

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

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

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INTRODUCTION

In NSW, approximately 854,300 people provide care and support to a family member or friend living with disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. This includes 273,900 primary carers (individuals who provide the majority of care to a person), and 83,700 young carers aged 25 and under.

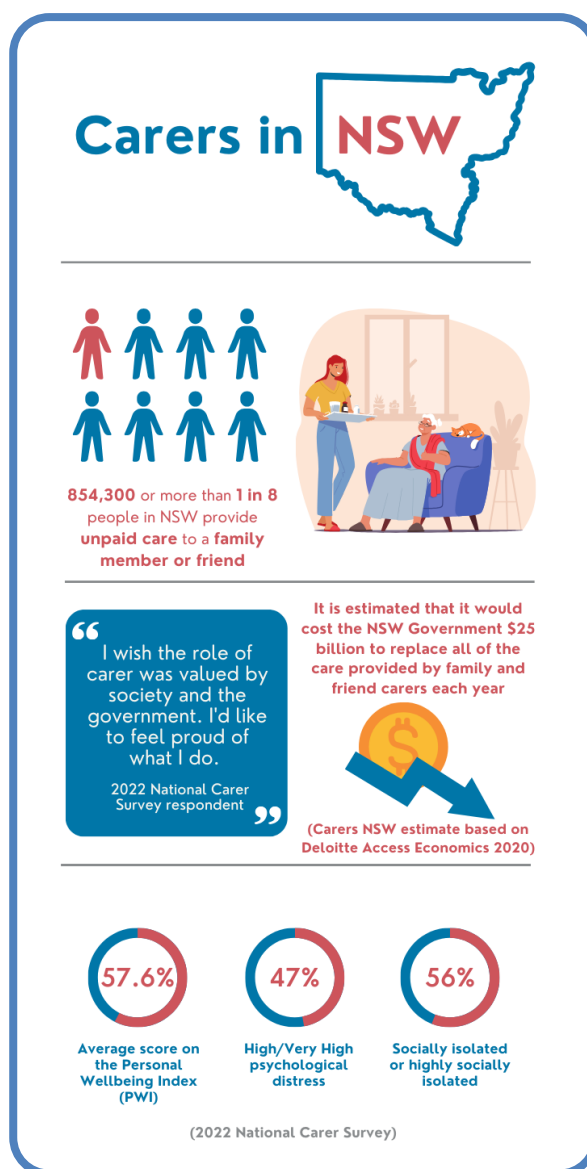
While many carers choose to care and report positive aspects of providing care, caring can have significant impacts on a carer's health and wellbeing, as well as their social and economic participation. The most recent Carers NSW biennial Carer Survey (2022), delivered nationally since 2020 with the support of the State and Territory Carer Organisations, highlighted that carers in NSW report significantly lower wellbeing and significantly higher psychological distress and social isolation than other members of the community. Recent concurrent crises including natural disasters, COVID-19, and current cost of living and housing crises have only further exacerbated challenges for carers across NSW.

Over the past decade, significant reforms to the disability, aged care and carer support sectors have seen a shift to national, consumer directed service systems. While these reforms have enabled some carers and the people that they care for to access new and improved supports, many carers have reported a loss in services and supports. Additionally, the shift to person-centred care, an important step for progressing the autonomy and self-determination of people living with disability and older people, has seen an unintentional shift of focus away from the experiences and needs of carers, who are often still an integral part of a person's support network. This has resulted in an increase in carers not being able to access the support they need, when they need it.

The introduction of telephone and in-person services under Carer Gateway³, the national service system for carers, in 2020 was a welcome step towards improved support for carers. However, Carers NSW believes there is still an important role for the NSW Government in supporting carers through the provision of complementary carer-focused services and supports that address ongoing identified gaps. This includes awareness raising and supports for young carers and First Nations carers, initiatives that aim to improve carer employment, and an ongoing focus on increasing carer recognition and inclusion within NSW Government services and supports.

The *NSW Carers Strategy 2020-2030* and accompanying two-year action plans, co-designed with carers in NSW, provide a clear roadmap for improving outcomes for carers across four priority areas

³ www.carergateway.gov.au



over the current decade. Carers NSW commends the ongoing commitment of the NSW Government through the development and delivery of the first and second NSW Carers Strategy Action Plans. However, Carers NSW believes that the NSW Government's commitments to a fresh start for NSW and a change in approach to investment provide an opportunity to reflect and expand on current carer-focused initiatives to reimagine support for carers in NSW to better meet their ongoing unmet needs.

Furthermore, significant reforms to aged care and disability service systems are expected to continue into 2024-25 following the recent release of the reports of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, National Disability Insurance Scheme (NDIS) Review and the Royal Commission into Aged Care Quality and Safety. With these reforms further progressed, a clear path forward for aged care and disability services and support will be emerging, with significant implications for NSW residents using these service systems. These changes will provide welcome opportunities to improve support for carers across NSW but may also result in continued upheaval and confusion for many carers and the people they care for, who have already been navigating major system change and complexity for a number of years.

In light of the many challenges and changes of recent and current NSW State Budget periods, this Pre-Budget Submission highlights three key areas for ongoing and additional NSW Government investment that align with the *NSW Carers Strategy: Caring in NSW 2020-2030*: recognising the important role of carers in NSW, improving access to information, services and support, and supporting economic wellbeing through participation in education and employment. Engaging carers at all stages of service planning and delivery and meeting the unmet needs of carers are key priorities articulated in the NSW Carers Charter and NSW Carers Strategy. This Pre-Budget Submission makes a range of practical recommendations for how these important principles can be reimaged and further progressed in the 2024-25 NSW State Budget Period.

Improving outcomes for carers in NSW by...



Recognising the important role of carers



Improving access to information and support



Supporting economic wellbeing through participation

SUMMARY OF RECOMMENDATIONS

1. Recognising the important role of carers

- 1.1 Adequately resource the 2nd Action Plan for the NSW Carers Strategy to enable effective implementation (see page 10)
- 1.2 Explore opportunities to invest in sustainable carer-focused projects (see pages 10-11)
- 1.3 Ensure that the term carer is used consistently with carer recognition legislation in NSW legislation, policy, programs and communications (see page 11)
- 1.4 Resource ongoing and new initiatives that aim to improve carer recognition and inclusion in NSW Government service settings (see page 12)
- 1.5 Invest in carer-focused cost of living measures such as a NSW Carers Card (see pages 12-13)
- 1.6 Implement all of the recommendations outlined in the NSW Ageing and Disability Commission Advisory Board policy paper *Preparing for the future: Learning from the impacts of the COVID-19 response on older people, people with disability and carers in NSW* (see pages 13-15)

2. Improving access to information, services and supports

- 2.1 Invest in a pilot that enables the implementation of the full Carer Skills program (see pages 16-19)
- 2.2 Review discharge planning requirements for NSW public health settings to ensure adequate carer inclusion and support (see pages 16-19)
- 2.3 Expand the Carer Readiness Tool to support carers in other Local Health Districts (see pages 16-19)
- 2.4 Fund additional support to assist guardians and financial managers with service navigation, advocacy, legal support and administrative tasks (see pages 16-19)
- 2.5 Prioritise the implementation of a Supported Decision-Making framework within NSW legislation in consultation with key stakeholder groups, the sector and experts (see pages 19-20)
- 2.6 Invest in evidence-based pilot projects that aim to provide education, resources and support that enable Supported Decision-Making approaches (see pages 19-20)
- 2.7 Continue to resource the development and rollout of evidence-based abuse prevention resources and training to carers, service providers and the wider community (see pages 21-22)
- 2.8 Continue and expand investment in supportive, evidence-based approaches to family conflict resolution such as elder mediation services (see pages 21-22)
- 2.9 Explore opportunities in the 2024-25 NSW Budget to fund systemic education projects that improve awareness and support of carers by key community stakeholders identified in the discontinued 2023-25 CIP grant guidelines (see pages 22-24)

3. Supporting economic wellbeing through participation in education and employment

- 3.1 Invest in continuing the Carers + Employers accreditation program (see pages 27-30)
- 3.2 Extend and expand existing NSW Government funded job-readiness programs such as the Return to Work Pathways Program to be inclusive of all carers in NSW (see pages 27-30)
- 3.3 Reinstate the Return to Work program or explore alternative opportunities to address costs associated with entering or re-entering employment for carers, including replacement care, through small grants or financial packages (see pages 27-30)

- 3.4 Invest in targeted employment and job-readiness support for diverse and hidden carer cohorts (*see pages 27-30*)
- 3.5 Expand on employment supports for carers through the Carers + Employment Hub (*see pages 27-30*)
- 3.6 Invest in programs to support young carers in their final years of high school to achieve optimal education outcomes and transition into further economic activities (*see page 30-32*).
- 3.7 Extend and expand on the Young Carer Skills Project to support more young carers to enter employment (*see pages 30-32*)

1. Recognising the important role of carers

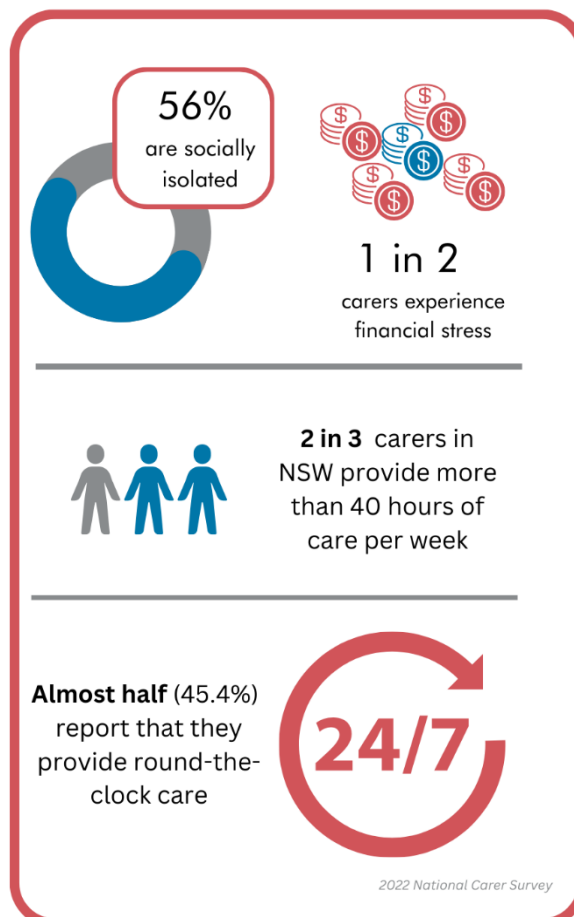
Across NSW, there are approximately 854,300 carers.⁴ Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical, and financial impacts that can also affect their participation in employment, education and community activities. According to Deloitte Access Economics estimates, to replace the care provided by carers, the NSW Government would have to spend more than \$25 billion each year.⁵

Findings from the Carers NSW 2022 National Carer Survey indicate that respondents from NSW experience significant impacts of caring, reporting lower wellbeing and higher psychological distress than the general population. Additionally, 56% report being socially isolated and 48% report experiencing financial stress.⁶

Carers in NSW provide high levels of care. The Carers NSW 2022 National Carer Survey found that almost two in three respondents (64.8%) provided 40 hours of care per week, with almost half (45.4%) providing 24/7 care.⁷ While this care should complement the care and support available through formal service systems, increasing demand for formal care in the context of ongoing negotiations about responsibility by State and Federal governments and workforce and market shortages within the care and support sector means that carers are taking on an increasing amount and complexity of care to fill service gaps within NSW.

The latest Intergenerational Report has projected that due to an ageing population, the growing demand for aged and disability care and higher expectations of care quality, the care and support workforce will need to double the size it was in 2020–21 by 2049-50.⁸ Given the increasing demand for care, the reliance on family and friend carers to support the formal care and support sector will only continue to grow. As such there will be an ongoing need to continue to prioritise recognition and support for carers in NSW to enable them to care sustainably into the future.

The NSW Department of Communities and Justice's (DCJ's) ongoing work with Carers NSW and other key stakeholders in implementing the NSW Carers Strategy and promoting the NSW *Carers (Recognition) Act 2010* and NSW Carers Charter reflects the NSW Government's genuine commitment to collaboratively improving outcomes for carers. However, challenges continue for many carers in the



⁴ Australian Bureau of Statistics (ABS) (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, New South Wales Tables, Canberra.

⁵ Carers NSW estimate based on Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*, Carers Australia.

⁶ Carers NSW (2022) *2022 National Carer Survey, unpublished data*.

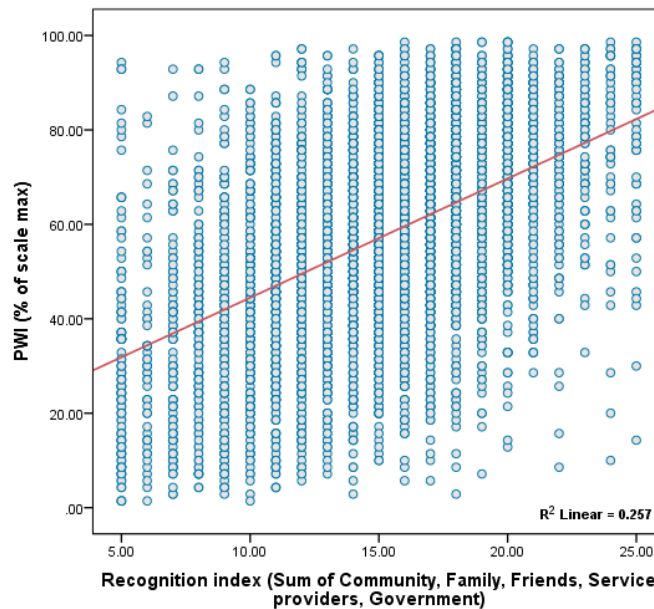
⁷ Ibid.

⁸ Australian Government (2023) *2023 Intergenerational Report*, available online at: <https://treasury.gov.au/publication/2023-intergenerational-report>, viewed 10 November 2023.

areas of recognition and inclusion, providing additional opportunities for NSW Government departments and agencies to work innovatively and engage more with carers and the people they care for.

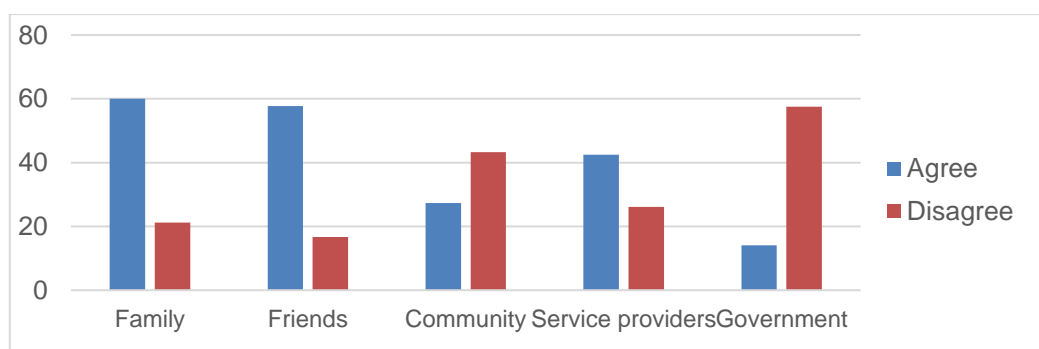
The Carers NSW 2022 National Carer Survey⁹ identified a strong relationship between carer recognition and carer wellbeing, with higher recognition associated with better wellbeing, and vice versa (see Figure 1).

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



Despite the NSW Government’s ongoing commitment to carer recognition, the Survey also found that carers in NSW continue to report low levels of recognition across a range of domains.¹⁰ Only two in five NSW respondents felt that their caring role was recognised by service providers, just over one in four felt recognised by the community, and just under one in seven reported that they felt recognised by governments (see Figure 2).¹¹

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



While self-reported levels of recognition in most domains remain low, positively, in 2022 carers in NSW reported higher levels of recognition by family, friends, service providers and the community than in the

⁹ Carers NSW (2022)

¹⁰ Ibid.

¹¹ Ibid.

2020 National Carer Survey.¹² However, compared to 2020, carers in NSW reported lower levels of recognition by government in 2022. While ‘government’ in this context could refer to any level of government, findings from the Survey regarding services primarily delivered by the NSW Government (public health and mental health services) indicate that carers are often not asked about their own needs or provided with adequate support to meet their needs.¹³ Accordingly, Carers NSW urges the NSW Government to continue advancing its commitment to implementing the NSW Carers Strategy.

Resourcing the implementation of the NSW Carers Strategy

The NSW Government has made a 10-year commitment to supporting carers in NSW through the *NSW Carers Strategy: Caring in NSW 2020-2030*. 2023 marks the first year of the *NSW Carers Strategy 2nd Action Plan: 2023-24*.

Projects delivered under the NSW Carers Strategy create opportunities to provide targeted information, support and policy responses that address carers’ needs across four identified priority areas. Carers NSW welcomed the launch of the *NSW Carers Strategy 2nd Action Plan: 2023-24* in April 2023 as an ongoing commitment to carers in NSW. Carers NSW currently leads six projects and supports three additional projects under the current Action Plan, including projects focusing on carer rights education, carers’ financial wellbeing, carers and employment, carer-friendly workplaces, carer related research and young carer inclusion. A number of other important initiatives led by a range of organisations and agencies address different groups of carers where specific needs have been identified, including Aboriginal and Torres Strait Islanders and young carers identified in schools.

Carers NSW looks forward to continuing to work closely with the NSW Government and other key stakeholders in progressing and delivering these activities. Carers NSW also encourages ongoing resourcing of projects and initiatives delivered under the NSW Carers Strategy and associated Action Plans throughout the remainder of the Strategy to ensure that it achieves its objectives.

Recommendations

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| 1.1 | Adequately resource the 2nd Action Plan for the NSW Carers Strategy to enable effective implementation |
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Investing in carer-focused projects

Despite the introduction of the *NSW Carers (Recognition) Act 2010* (the Act), awareness and recognition of carers in the community thirteen years on remains low, and is reflected in carers’ self-reported feelings of limited recognition by service providers, government and communities.¹⁴ Awareness and identification of carers is key to enabling carers to access support and tailored responses that address the complex and nuanced needs associated with their caring role.

The NSW Carers Investment Program (CIP) has previously supported the implementation of the Act and NSW Carers Strategy by enabling the delivery of carer-focused projects aimed at building carers’ capacity and improving awareness of carers in the community. The CIP 2023-25 grant round opened in February 2023 and focused on innovative projects to build the capacity of service providers and professionals in identifying and supporting carers. This grant round provided an important opportunity for new projects led by a range of organisations and sectors to support the implementation of the NSW

¹² Carers NSW (2020a) *2020 National Carer Survey*, unpublished data.

¹³ Carers NSW (2022).

¹⁴ Ibid.

Carers Strategy and NSW *Carers (Recognition) Act 2010*. Carers NSW was therefore disappointed by the decision in June 2023 to discontinue the second assessment phase for successful Expressions of Interest for the funding.

Carers NSW and a wide range of other stakeholders had identified and proposed a number of systemic education projects aimed at improving awareness and support for carers at key touchpoints in the community, including GPs and other health professionals, pharmacists, teachers and principals, and government agencies that carers come into contact with. The discontinuation of this funding commitment leaves a significant gap in the awareness raising resources available to support the implementation of the NSW Carers Strategy and *NSW Carers (Recognition) Act 2010*. Carers NSW believes that to continue to improve awareness, recognition, and support for carers in NSW, in addition to resourcing the NSW Carers Strategy Action Plan, investment in carer-focused projects and programs that address known barriers to or gaps in carer support is key to ensuring optimal outcomes for carers.

Recommendations

- 1.2 Explore opportunities to invest in sustainable carer-focused projects

Ensuring consistent use of the term carer in NSW Government policy and programs

The introduction of the *NSW Carers (Recognition) Act 2010* (the Act) established the definition of a carer in NSW as an individual who provides care or support to a family member or friend due to disability, mental illness, chronic illness or frailty and ageing. While this definition is clearly stated, Carers NSW has observed that there continues to be considerable conflation within government, among service providers and in the broader community between carers and parents, foster carers and kinship carers. Carers NSW believes that ensuring that NSW Government communications, policies and programs use the term carer in line with NSW carer recognition legislation may assist with reducing the misuse of the term carer, and help to create a more consistent understanding of who is and is not a carer.

Carers NSW acknowledges that foster and kinship carers experience a range of challenges associated with their foster or kinship care arrangements. Foster and kinship carers play their own important role within the community, however, the relationship between foster or kinship carers and the person they care for is parental in nature, with the provision of care that would otherwise be provided by another parent or guardian, which does not meet the definition of a carer under the Act.

While some foster and kinship carers may be providing care and support to a child with disability, chronic illness, life limiting illness or mental illness, in these instances, the foster or kinship carer would meet the established definition of a carer within the Act and the provisions outlined within the rest of the Act and other relevant legislation and policy would apply to them. Carers NSW believes that referring to foster and kinship carers as 'carers' not only creates confusion in relation to eligibility and focus of policy and program measures, but it may also have a negative impact on carers perceived recognition. Furthermore, ensuring that foster and kinship carers are correctly identified when referenced will ensure that these groups are also appropriately recognised and supported through their own legislative or policy instruments.

Recommendations

- 1.3 Ensure that the term carer is used consistently with carer recognition legislation in NSW legislation, policy, programs and communications

Continuing existing carer-focused initiatives

Throughout 2022 and early 2023, Carers NSW was involved in a number of collaborative initiatives with NSW Government agencies which were focused on improving carer recognition within NSW policies and programs. Projects included but were not limited to:

- NSW Department of Customer Service's digital identity project, which was exploring opportunities to identify carers as representatives and within their own right in Service NSW IT infrastructure,
- Service NSW work with Carers NSW to improve information and support for carers on their website and within service centres,
- The NSW Ageing and Disability Commission's carer research project which aims to understand and better support carers in the context of preventing abuse and neglect of people with disability and people who are ageing, and
- Anti-Discrimination NSW ongoing work to improve information and support for carers experiencing or at risk of experiencing discrimination.

Carers NSW acknowledges the ongoing work of NSW Government departments and agencies to improve carer recognition and inclusion through these collaborative initiatives. Carers NSW also recognises the ongoing commitment of the NSW Government to create carer-inclusive workplaces with the accreditation or commitment to achieving accreditation of six NSW Government agencies and departments through the Carers + Employers program.

Carers NSW encourages the NSW Government to continue to resource existing and new initiatives that aim to improve carer recognition for carers as service users and employees within NSW Government service settings. Improved recognition is likely to support carers to better access existing services and supports delivered by the NSW Government.

Recommendations

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| 1.4 | Resource ongoing and new initiatives that aim to improve carer recognition and inclusion in NSW Government service settings |
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Recognising carers through carer-focused cost of living measures

Carers face unique financial and housing stresses associated with their caring role which Carers NSW has continued to raise with NSW and Federal governments. Carers NSW commends the new NSW Government on its commitment to increasing access to affordable housing and revisiting the minimum accessibility standards of the National Construction Code. Addressing housing shortages and affordability across NSW will likely support more carers to secure affordable, appropriate housing, and reduce broader financial strain on carers.

Carers NSW also welcomes the increase in energy rebates announced in the 2023-24 NSW Budget. However, Carers NSW is concerned that a number of cost of living schemes and initiatives were discontinued or reduced in the 2023-24 NSW Budget, this includes but is not limited to the Regional Seniors Travel Card, Regional Apprentice and University Student Travel Card, and the discontinuation of the toll rebate. Additionally, Carers NSW was disappointed to see there were a lack of carer-focused cost of living measures within the Budget that aimed at addressing the significant financial strain currently being experienced by carers in NSW.

In addition to a lack of new measures, Carers NSW also has concerns that there is confusion about the focus of the NSW Companion Card, with the NSW Carers Strategy Action Plans and recent NSW State Budget communications positioning the Companion Card as a measure to address financial pressures on carers. While the Companion Card is an important initiative in supporting the inclusion of people with disability in community life which may have flow on effects for some carers, the intent of this initiative is not to address carer financial strain, and in many cases, is used by paid support workers.

The Companion Card was introduced to enable people with significant and permanent disability to participate in community activities without them having to cover additional ticketing costs to enable their support person, who may be their carer, to accompany them and provide care. Eligibility for the card requires that attendant care, or a high level of care, is provided that constitutes 'significant assistance with mobility, communication, self-care or planning'.¹⁵ While it may be perceived that carers may experience a flow on effect of access to this card through subsidised or concessional entry to activities or events, the intent of the card is not to enable carers to participate in recreational activities themselves, but to support participation of the person/s they support in social and community activities.

Additionally, the Companion Card is applied for and held by an individual living with disability. It cannot be held by a carer in their own right and cannot be accessed by a carer to participate in activities of their own choosing where they are not accompanying the person they care for. Access to a Companion Card is also limited to carers of people living with disability and other cohorts of carers may be unable to access this measure as such.

Carers NSW believes that in addition to initiatives that support the participation of people living with disability in community life by providing subsidised entry or tickets, the Government must also invest in carer-focused cost of living initiatives that address costs associated with participation in social and recreational activities for carers in their own right. Carers NSW continues to advocate for the introduction of a Carer Card in NSW which may provide access to concessions and subsidies for carers, similar to Carer Card programs established in other states including Victoria¹⁶ and Queensland¹⁷, recognising carers in their own right and better meeting carers own financial needs.

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

- Carers NSW 2022 National Carer Survey respondent

Recommendations

1.5 Invest in carer-focused cost of living measures such as a NSW Carers Card

Preparing for future pandemics and health events

COVID-19 has had significant impacts on all NSW residents. However, many carers and the people they care for, including older people and people living with disability have experienced exacerbated and

¹⁵ <https://www.nsw.gov.au/community-services/companion-card/about-card>

¹⁶ <https://www.carercard.vic.gov.au/>

¹⁷ <https://www.qld.gov.au/community/support-for-carers/carers-card>

additional impacts as a result of their increased susceptibility and exposure to the virus, and their higher-than-average reliance on services and support networks that were disrupted by protective measures.

In 2022, Carers NSW prepared a paper on behalf of the NSW Ageing and Disability Commission Advisory Board, launched in June 2023, that drew together the public evidence on the impact of the COVID-19 response in NSW on older people, people living with disability and carers. The final paper, *Preparing for the future: Learning from the impacts of the COVID-19 response on older people, people with disability and carers in NSW*,¹⁸ looks at the experiences of these target groups, and highlights issues to be addressed and opportunities to improve planning for future pandemics.

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

- Carers NSW 2022 National Carer Survey respondent

The paper also recognises positive steps taken by the NSW Government during the response to the pandemic, including improvements in communication between Government agencies and people with disability and their carers through the establishment of targeted communities of practice, the provision of new funding or more flexibility with existing funding to better meet emerging needs throughout the pandemic and engagement with the Federal Government to enable whole-of-government responses to outbreaks in aged care settings.

The paper includes 28 recommendations for the NSW and Australian Governments, 24 of which have relevance to the roles and responsibilities of the NSW Government. Recommendations are grouped under five key areas:

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

¹⁸ Carers NSW (on behalf of the NSW Ageing and Disability Commission Advisory Board) (2023) *Learning from the impact of the COVID-19 response on older people, people with disability and carers in NSW*, available online at: https://www.ageingdisabilitycommission.nsw.gov.au/content/dam/dcj/ageing-disability-commission/documents/Impacts_of_COVID-19_Background_Paper_June_2023.pdf, viewed 10 November 2023.

Carers NSW recommends that the NSW Government review and implement the recommendations from the paper to plan for future pandemics and to ensure that the preparation for and response to future pandemics or health events is inclusive of carers and the people they care for, and reduces the impact of these events on vulnerable groups.

Recommendations

- 1.6 Implement all of the recommendations outlined in the NSW Ageing and Disability Commission Advisory Board policy paper *Preparing for the future: Learning from the impacts of the COVID-19 response on older people, people with disability and carers in NSW*

2. Improving access to information, services and supports

While many carers choose and plan to take on caring responsibilities, for others, caring can begin unexpectedly with minimal opportunity to prepare. Irrespective of how or when a caring role may begin, it is not uncommon for carers to report challenges with navigating complex service systems, or developing practical caring skills that are essential in supporting them to provide safe and sustainable care.

To adequately understand the impact of limited access to services, information, and support, it is important to first demonstrate the level of care and support carers often provide to their family members and friends, even where formal services are in place. It is also necessary to draw attention to how care and support systems (inclusive of health, mental health, aged care and disability), heavily rely on informal care arrangements especially as the delivery of care services have gradually shifted away from formal care settings into the home and community.¹⁹

Data from the Carers NSW 2022 National Carer Survey indicates that on average, carers in NSW have been caring for more than 10 years,²⁰ and provide a wide variety of care tasks that may range from practical supports such as personal care, transport, meal preparation and medication management, to emotional and cognitive supports including advocacy, administration, and service coordination (Figure 3).

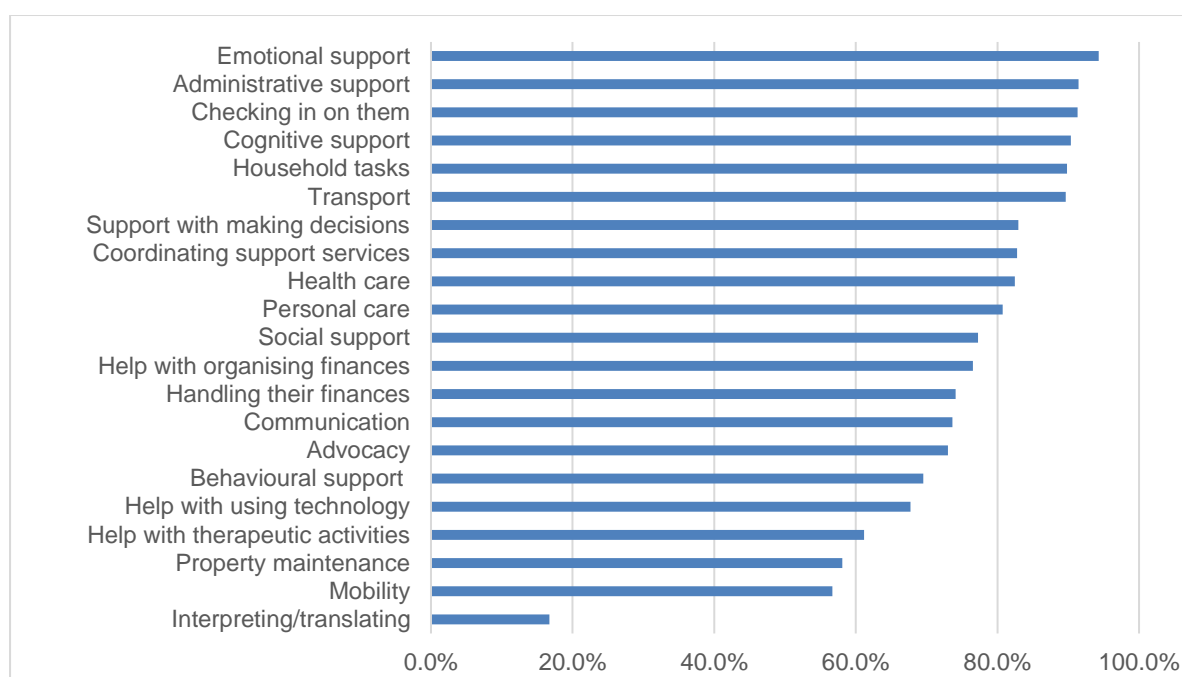
Despite the clear role carers play in the care and support of their family member or friend, Carers NSW has continued to hear from carers about the lack of information and support they can access at critical points of their caring journey as well as during key points of contact with formal care systems. Although the NSW *Carers (Recognition) Act 2010* and NSW Carers Charter provide clear guidance for public service and human service agencies to ensure carers are adequately supported to provide care in a way that positively contributes to their health and wellbeing and social and economic participation – which includes ensuring they are adequately prepared to take on and maintain a caring role. Data from the 2022 National Carer Survey demonstrates that these principles are not always consistently upheld. The Survey found that that in NSW only one in three carers reported that they had been provided with the necessary information required to support them in their caring role and almost 70% reported that they were not asked about their own needs²¹ when engaged in health care settings.

¹⁹ White, S., Hart, N., & Lewis, S. (2021), 'Engaging Carers in Co-Design: Development of the Carer Readiness Tool, International journal of integrated care, 21(1), 13. <https://doi.org/10.5334/ijic.5527>.

²⁰ Carers NSW (2022).

²¹ Ibid.

Figure 3. Care tasks undertaken by carers in NSW



Carers NSW has raised the issue of adequate access to information, services and supports in previous Pre-Budget Submissions and other consultation opportunities, and wishes to again highlight that through investment in support and capacity building initiatives for carers, former carers and the service systems they engage with, carers are likely to be better equipped to provide sustainable care, as well as to be able to effectively transition out of the caring role, resulting in better long-term outcomes for carers and the people they care for.

This section will draw attention to existing programs and initiatives that support carers to develop skills and understanding of best practice approaches to provide safe and sustainable care. Carers NSW believes that there are a number of opportunities to expand on these initiatives to provide state-wide coverage across all care settings.

Investing in carer skills training

Beyond data collected in the 2022 National Carer Survey, the critical role carers play in the care and support of their family member or friend have also been identified in recent findings from the Royal Commissions into aged care and disability, as well as inquiries into carer recognition and Carer Leave, and the draft National Strategy for the Care and Support Economy.

Findings from the Royal Commission into Aged Care Quality and Safety (the Aged Care Royal Commission) have strengthened the case for the needs of carers to be adequately considered when planning and coordinating the care of older people, ensuring they have the adequate skills, knowledge, and training to manage the changing care needs of their ageing family member or friend. The findings from the Aged Care Royal Commission are applicable to the experiences and service needs of all carers and demonstrate the need for a consolidated and integrated approach to carers skill development. Carers NSW believes the NSW Government could invest in existing pilot programs where carers are supported to develop their knowledge and confidence in practical caring skills that supports safe and sustainable care arrangements.

Supporting sustainable care arrangements through developing practical skills

The Consumer and Carer Coaching Program (3CP), a project led by Carers NSW and funded through the Commonwealth Home Support Programme's (CHSP) Innovation Fund, was developed in consultation with carers to build the practical caring skills of carers to meet the demands of increasing care needs.

Through programs like the 3CP, now delivered as the Carer Skills program, carers of older people 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 care and support sector. Carers NSW has previously advocated for skills-based programs such as 3CP to be funded more broadly by the NSW Government to support all carers to prepare for and navigate a change in their caring role and believes such resources could be developed to support carers engaging in different service systems i.e. health, mental health or disability, to feel confident in providing practical caring skills that specifically relate to their caring role.

Carer inclusive discharge planning

Carers NSW has previously highlighted the importance of carer-inclusive discharge planning, as there is strong evidence to suggest that inclusive and collaborative discharge planning between hospital staff and carers results in fewer hospital admissions,²² particularly as carers are likely to coordinate and provide care in conjunction with outpatient services. Despite the clear benefits of including carers in conversations around discharge planning, many carers continue to report they are not readily prepared for, or at times are even informed about, the discharge of their family or friend into their care at home or in the community.

The Carer Readiness Tool (CRT), developed by Central Coast Local Health District (CCLHD) Carer Support Unit, is a three-pronged initiative that was launched in response to an identified need for carers to be better equipped to support family members or friends as they are discharged into the community. The CRT gauges carer readiness and confidence to undertake clinical tasks in the home, indicating to clinical staff any areas where carers may require support and providing evidence that CCLHD is engaging carers as partners in care – an obligation under the NSW Carers Charter.

Experiences of the CRT have been closely monitored, with respondents who participated in the pilot conveying their appreciation for being asked about their own needs when they prepared for their care recipient's discharge.²³ Further, respondents also indicated the benefit of having the opportunity to identify competing care responsibilities, existing formal or informal supports, as well as convey any concerns they had without having to express them in front of the person they care for.²⁴

From an international perspective, the online carer support service Mobilise has developed the Carers Guide to Hospital Discharge, a resource which collates information from the United Kingdom's National Health Service (NHS) and other sources to provide family and friend carers with centralised information about discharge planning. The resource provides carers with guidance and advice on how to plan for their care recipient's discharge, including information on where to find practical support that enables a smoother transition from the clinical environment into the community.

Both the CRT and online resource demonstrate the importance, but also the need, for supports within the health care system that are specifically tailored to the needs of the carer. By implementing well

²² Rodakowski, J., Rocco, P., Ortiz, M., Folb, B., Schulz, R., Morton, S., (2017), Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis, *Journal of the American Geriatric Society*, 65(8): 1748–55. DOI: 10.1111/jgs.14873

²³ White et al (2021).

²⁴ Ibid.

practiced initiatives across all health systems in NSW, Carers NSW believes that carers will be supported to provide care in a safe and sustainable way.

Supportive service navigation

Further to investment in practical skills development, Carers NSW has continued to observe an unmet need in carers seeking support and guidance in system navigation. At the time of writing, there are few, if any, NSW Government funded programs that exist where carers and the people they care for are supported in the navigation of what are often extremely complex and confusing systems. Of the programs that do exist, they are often confined to specific service systems such as mental health and limited to certain regions, creating frustration among those who are aware of supports but due to their location or caring role, cannot access them.

The need for adequate and support service navigation – an issue that is particularly prevalent in the context of disability and aged care services – has also been captured in the 2022 National Carer Survey, where respondents in NSW 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.²⁵

Further, carers usually navigate multiple specialist and mainstream service systems at the same time, often spending considerable time doing so as centralised information and assistance is very limited, often out of date or hard to find, with most being provided as online resources that can be inaccessible for some carers. Many of the service systems carers navigate are NSW Government funded, such as hospital and community health services, and 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.²⁶

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. 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 living with disability and their families and Ability Links NSW. Carers NSW welcomes the centralisation of support for carers through the Service NSW website and introduction of cost-of-living specialists in Service NSW centres as an important starting point in centralising the service information available to carers. However, Carers NSW believes that there is a need to continue to build on these initiatives to provider broader service navigation support for carers across NSW who are navigating multiple NSW Government services and systems.

Support carers to navigate guardianship systems in NSW

Carers NSW has continued to hear from carers that they have had significant difficulties accessing or implementing services or supports with or on behalf of the person they care for due to complex guardianship arrangements, specifically where another family member may be an identified legal guardian. Carers NSW has concerns that where services are unable to be enacted due to difficulty obtaining approval from an appointed guardian, especially where a guardian may not be living in the same household as the person they care for or providing direct care, this can have severe negative outcomes for both parties. In some cases, it may even result in a breakdown in caring arrangements or risks to the health and safety of the care recipient.

²⁵ Carers NSW (2022).

²⁶ Ibid.

Furthermore, carers experiencing difficulty accessing services due to guardianship arrangements have expressed frustration with the complexities of the guardianship system. Carers report that it is not clear what they need to do to overcome guardianship issues in order to obtain consent to initiate services, and they are often referred to the incorrect places for support. Inappropriate referrals and incorrect information often delay the initiation of services and places carers under a high level of psychological distress.

Recent changes to substitute decision maker legislation in the context of the aged care sector where those providing substitute consent on behalf of an older person to use restrictive practices are now required to enter legal guardianship arrangements, are likely to further compound the known challenges and concerns carers currently experience.

Carers NSW believes that the NSW Government must invest in greater support for carers engaging with guardianship systems to assist them with service navigation and advocacy in complex circumstances. Additionally, Carers NSW believes that there must be an urgent review of the NSW guardianship system to ensure that there are adequate mechanisms in place to enable immediate approval of services where this is in the best interest of a carer and the person they care for, and this approval is unable to be sought from a guardian or a guardian does not agree with the need for formal services or supports.

Joe cares for his father Paul* who lives with him. Paul lives with dementia, and his condition declined during the COVID-19 lockdown. Joe recently injured his back while providing care and feels that formal services are now needed to enable Paul to continue living at home with him, as his support needs are increasing. Paul has a Level 3 Home Care Package, however his legal guardian Kim*, Joe's sister, will not consent to services as she is concerned that this will take money from Paul's estate. Joe contacted the NSW Civil and Administrative Tribunal (NCAT) for support, however has been unable to complete the required paperwork to request a tribunal as he is feeling so overwhelmed with his caring role and how to overcome this issue.*

** Names changed*

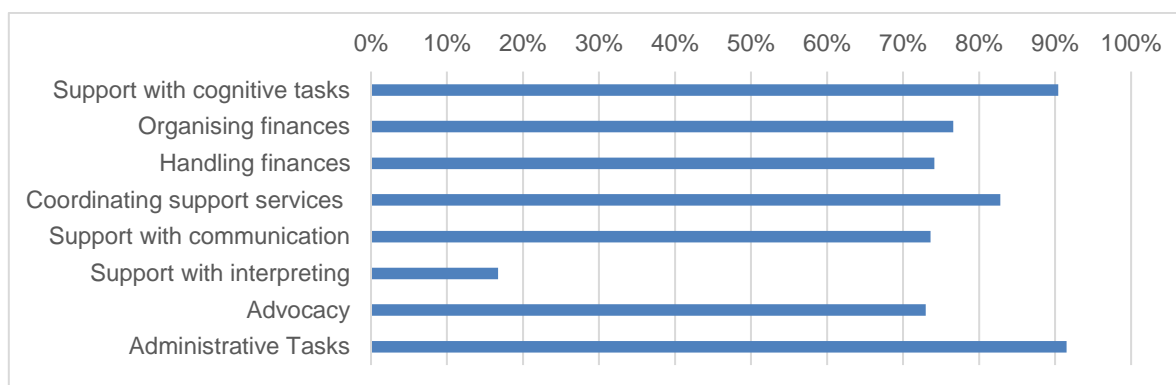
Recommendations	
2.1	Invest in a pilot that enables the implementation of the full Carer Skills program
2.2	Review discharge planning requirements for NSW public health settings to ensure adequate carer inclusion and support
2.3	Expand the Carer Readiness Tool to support carers in other Local Health Districts
2.4	Fund additional support to assist guardians and financial managers with service navigation, advocacy, legal support and administrative tasks

Investing in supported decision-making education and training

Many carers in NSW support the person that they care for to make decisions, however there are limited opportunities for carers to receive formal training or support with this. The Carers NSW 2022 National Carer Survey¹⁷ found that approximately 83% of NSW respondents provided support with decision making. The Survey also found that carers provided support with a number of tasks that are associated with making, executing and communicating decisions (Figure 4). Furthermore, 90.4% provided support with cognitive tasks, 76.6% with organising finances, 74.1% with handling finances and 82.8% with

coordinating support services. Additionally, 73.6% provided support with communication, 16.7% with interpreting, 73% with advocacy and 91.5% with administrative tasks, all of which can play a key role in making, executing, and communicating decisions.

Figure 4. Care tasks supporting making, executing, and communicating decisions



While carers often support the person they care for to plan for the future, these discussions can be sensitive, confronting and challenging to navigate. Many carers express concerns about making future care decisions on behalf of the person they care where they may experience reduced decision-making capacity, wanting to make the 'right' decision that would align with their will and preference. Others have also expressed the difficulty in understanding and navigating the service systems in which supported or substitute decision making exists.

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

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

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

Recommendations	
2.5	Prioritise the implementation of a Supported Decision-Making framework within NSW legislation in consultation with key stakeholder groups, the sector and experts
2.6	Invest in evidence-based pilot projects that aim to provide education, resources and support that enable Supported Decision-Making approaches

Preventing, identifying, and responding to abuse and neglect

Carers are often portrayed as perpetrators of abuse against vulnerable persons in the community. While it is true that a large proportion of instances of abuse and neglect involve family members, the recent Aged Care and Disability Royal Commissions have also highlighted the invaluable role of carers as observers and reporters of potential abuse and neglect. Carers NSW has provided a series of submissions to each of these Royal Commissions, detailing the role carers often play in reporting and responding to violence, abuse and neglect. We have also used these inquiries to highlight that some carers may also be at risks of being victims of violence and abuse themselves.

In NSW, the Ageing and Disability Commission (ADC) is the key agency who monitors and investigates reports of violence, abuse and neglect of older people and people with disability in the community, while also working closely with the community to promote the rights of people with disability and who are ageing. Since the establishment of the ADC, Carers NSW has worked closely with the ADCs since its establishment to ensure that family and friend carers are recognised for their valuable roles in identifying and responding to abuse, but also to ensure that approaches to mitigating against potential violence, abuse and neglect – which may be perpetrated by carers – are appropriate and inclusive of carers.

This section will draw attention to the need for continued targeted investment in education and support for carers to prevent abuse and neglect, and will highlight opportunities for existing projects currently delivered by the ADC to carry over within the next NSW Budget.

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

In some instances, inadequate formal or informal support in the community for carers or the people they care for can lead to carer stress or a breakdown in caring relationships, which can in turn increase the risk of harm to the carer or the person they care for. Data analysed by the ADC, UNSW and Carers NSW has supported anecdotal evidence that a lack of formal services, combined with inadequate carer support and training can be contributing factors to incidences of abuse or neglect towards people with disability or older people.²⁷

Carers NSW has continued to work closely with the ADC, carers and relevant stakeholders in developing a suite of resources for carers and the community more broadly to adequately identify and respond to incidences of abuse or neglect, but to also confidently identify and respond to signs of carer stress which can often determine if a carer is at risk of perpetrating abuse or neglect. Beyond community facing resources, Carers NSW has also developed resources for those investigating reported incidents of abuse and neglect to adequately identify and support carers as a way to prevent against future and neglect from occurring in the community. Carers NSW believes ongoing investment in building carer capacity is likely to continue to reduce and ultimately prevent abuse and neglect in the community.

Ongoing monitoring and improvement of the data regarding abuse and neglect, and carers' roles within these situations, will also be important additions to the national conversation about abuse prevention. Carers NSW also commends the NSW Government on the continued funding this financial year of Relationships Australia NSW Let's Talk Elder Support and Mediation Service²⁸, which we believe provides a valued and effective pathway for resolving potential conflict within families and supports optimal outcomes for people who are ageing and their carers. However, we underscore the importance of longer term, sustainable funding for such initiatives to ensure continuity and equity of access. In addition to securing ongoing resourcing for this important work, Carers NSW also believes that the

²⁷ Broady, T., Thomson, C., Hill, T., Katz, I., & Judd-Lam, S (2022) *Carers project: Research Report, NSW Ageing and Disability Commission*, unpublished.

²⁸ <https://www.relationshipsnsw.org.au/support/services/lets-talk-elder-mediation/>

eligibility for such services should also be expanded to carers in their own right, and beyond the ageing context alone to include other caring situations.

Recommendations

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

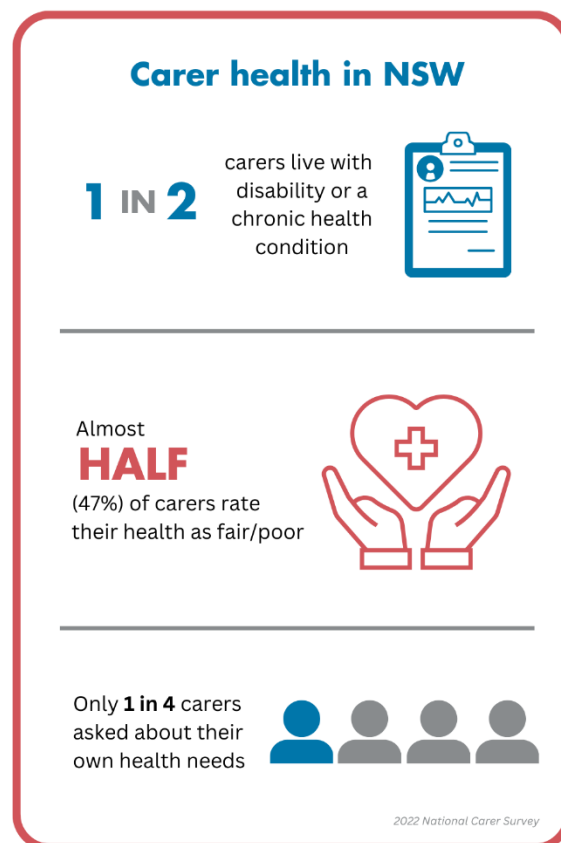
Building the capacity of mainstream services and supports to identify and support carers

While it is important to support carers to develop practical skills necessary for their caring role, it is equally important to ensure that the services and systems they engage with are adequately equipped to recognise and support them. Current provisions under the NSW *Carers (Recognition) Act 2010* and the NSW Carer Charter provide clear instructions for public and human service agencies to recognise, include and support family and friend carers. Carers NSW has previously raised concerns regarding the effectiveness of these principles, especially as data from consecutive Carers NSW biennial Carer Surveys has indicated that carers do not always feel appropriately recognised and supported when engaging with government agencies or service providers.

The discontinued Carer Investment Program (CIP) 2023-25 aimed to improve carer recognition in mainstream services by funding systemic education projects to assist stakeholders such as General Practitioners, pharmacists, school teachers and government services to better identify and support carers. Following the discontinuation of the CIP grants process in June 2023, Carers NSW urges the NSW Government to consider alternative opportunities to fund systemic education projects aimed at improving carer recognition in the 2024-25 NSW Budget.

Improving carer awareness and recognition in general practices

Similar to other service systems, carers often have regular contact with a GP with or on behalf of the person they care for. Despite their high engagement with GPs and clinic staff, many carers report their own health needs often go unmet, with only approximately 1 in 4 (28.6%) being asked about their own needs in primary healthcare settings.²⁹ Carers often report worse health outcomes than other Australians and tend to delay or neglect their own health needs, prioritising the health and care needs of the person they care for. Some carers have also



²⁹ Carers NSW (2022).

reported that GPs and clinic staff have a limited understanding of carers and the role they play, and this can create further barriers to accessing effective healthcare.³⁰

Carers NSW has raised the importance of carer awareness among GPs in previous Pre-Budget Submissions and consultation opportunities with the NSW Government, highlighting the close relationship between carer recognition and better health outcomes for carers. To ensure that the health and wellbeing of carers continues to be a priority of the NSW Government, Carers NSW believes that targeted investment in education and training for GPs should be a funding priority in the next NSW Budget.

Supporting pharmacists to meet the needs of carers

Carers are highly involved in the care and support of their family member or friend and as such, it is not uncommon for them to provide practical assistance in that person's medication management, including collecting and delivering their medication. It is likely pharmacists and other staff working in the centre have regular and ongoing contact with family and friend carers. Additionally, with the promising NSW Pharmacies Trial underway, pharmacies and the various staff they employ are likely to have increased contact with carers and the people they care for. The appropriate and early identification of carers can be critical to timely access and uptake of carer supports that can improve the sustainability of the caring role.

Carers NSW believes that additional support should be provided to pharmacy staff as part of the Government's broader investment in the shifting role and responsibilities of local pharmacies. Given the high level of involvement of carers in the health and wellbeing of the person they care for, and their own health needs, Carers NSW urges the NSW Government to invest in state-wide carer-awareness training initiatives for pharmacists and pharmacy staff, developed and delivered in consultation with industry bodies.

Holistic support for young carers within schools

There are approximately 83,700 young carers in NSW.³¹ While many gain important skills from their caring role, there may also be implications for their health and wellbeing, and social and economic participation. For young carers engaged in education, it is not uncommon for them to report challenges in successfully balancing their care responsibilities and their responsibilities as a student. As a result, young carers have lower levels of educational attainment and workforce participation compared to their non-caring counterparts.³² Research also indicates that young carers have higher rates of absenteeism and may have difficulty in completing assignments or homework due to their caring responsibilities. Furthermore, young carers are less likely to finish year 12 and have a post-secondary education than non-carers of the same age.³³ Without adequate support, such issues can affect students' long term educational achievement and employment prospects.³⁴

Noting the systemic barriers that affect young carers participation in education, Carers NSW believes there is a need for increased investment in working directly with schools to support young carers balance their caring responsibilities and improve their long-term educational outcomes. The Building Supportive School Environments (BSSE) Program was a model developed by Carers NSW in response to the CIP 2023-25 opportunity builds on existing programs currently delivered by Carers NSW and seeks to work directly with school staff to co-design evidence-based young carer identification and

³⁰ Carers NSW (2022).

³¹ ABS (2018).

³² Cass, B, Brennan, D, Thomson, C, Hill, T, Purcal, C, Hamilton, M, and Adamson, E (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Report prepared for ARC Linkage Partners, October 2011.

³³ Ibid.

³⁴ Ibid.

referral pathways and models that allow young carers to experience holistically supportive school environments. Carers NSW recognises the need to support young carers excel in education and believes that by investing in this or similar initiatives, young carers will be enabled to better navigate pain points in educational transitions and to gain the skills and experiences necessary to secure gainful employment when they leave school.

Strengthening carer inclusion in government services

Service NSW provides many carers across NSW access and information about a wide variety of services and supports that may support them in their caring role. Carers NSW commends the work of DCJ and the Department of Customer Service (DCS) to date, where the unique service needs of carers have been recognised and supported through the development of tailored information and support, particularly through the launch of the dedicated carers landing page on the Service NSW website.

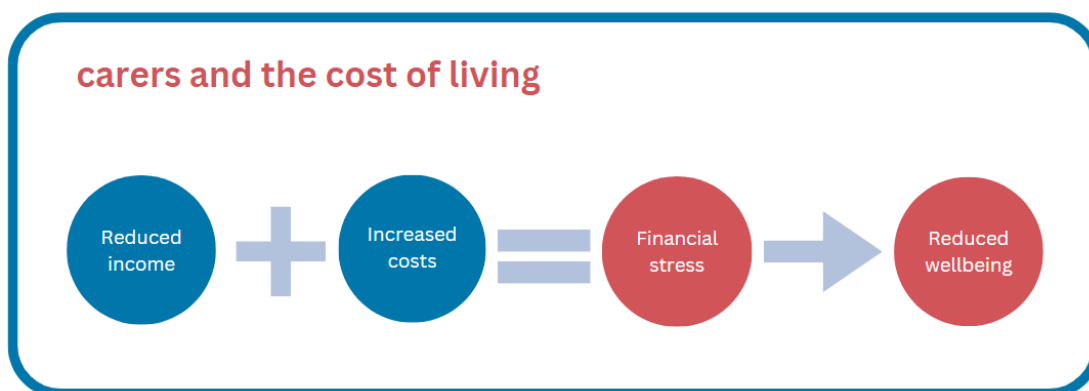
Despite the obvious commitment of DSC and Service NSW to improve their carer-inclusiveness, Carers NSW has identified variable knowledge and service experience across the agency, impacting the timeliness and appropriateness of support provided to carers. Carers NSW believes ongoing investment in raising the carer awareness of Service NSW teams will support them to provide tailored training and referral information to ensure that carers experience a seamless service experience when engaging with NSW Government services, whether online, over the phone or in Service Centres.

Recommendations

- 2.9 Explore opportunities in the 2024-25 NSW Budget to fund systemic education projects that improve awareness and support of carers by key community stakeholders identified in the discontinued 2023-25 CIP grant guidelines

3. Supporting economic wellbeing through participation in education and employment

The rising cost of living is affecting many people across NSW; however, carers face greater financial pressure due to their reduced earning capacity and higher financial costs as a result of their caring role. While many carers were already experiencing financial hardship, rising inflation and housing costs, and the expectation of continued natural disasters in the coming months signal the need for increased measures that support carers' financial wellbeing. For carers, support to meet their financial needs has never been more important.

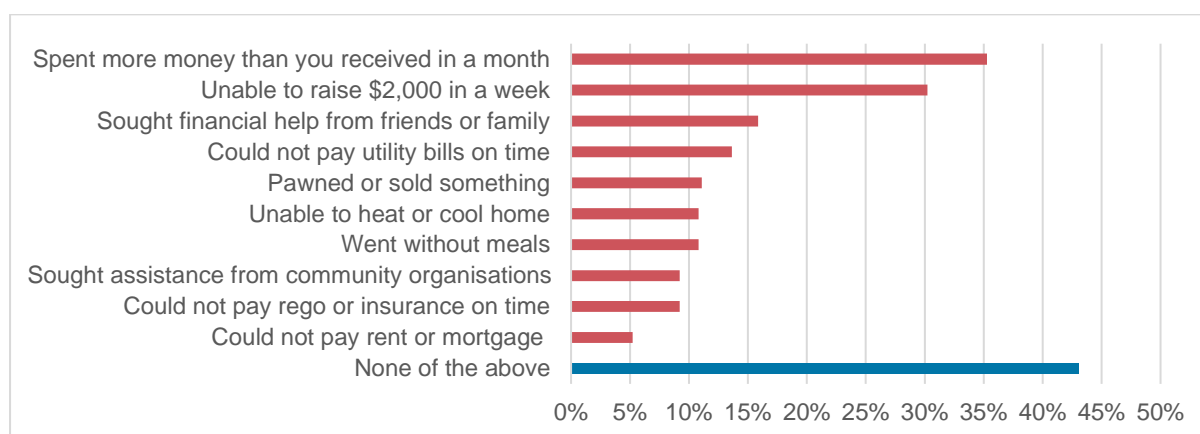


(2022 National Carer Survey Briefing: Carers and the cost of living³⁵)

³⁵ https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2022_National_Carer_Survey_Briefing_1_Carers_and_the_cost_of_living.pdf.

The Carers NSW 2022 National Carer Survey found that 52% of NSW respondents reported at least one experience of financial stress in the past 12 months, and 13.1% reported financial distress (four or more experiences of financial stress in the past 12 months).³⁶ Figure 5 demonstrates that almost 1 in 3 (30.2%) had been unable to raise \$2,000 in a week for something important and a similar proportion (35.3%) had spent more money than they received in a month. Additionally, in the Carers NSW 2020 National Carer Survey, 68.6% of carers reported paying for expenses relating to their caring role such as purchasing medicine and managing the costs of transport and accommodation.³⁷ Carers may also have higher utility costs and wear out white goods more quickly due to additional laundry, heating or cooling necessary to meet the needs of the person they care for.

Figure 5. Financial stress among carers in NSW



Analysis presented in 2022 by Evaluate in the *Caring Costs Us* report indicates that caring has significant impacts on carers' lifetime earnings and their ability to save for retirement. According to the report, primary carers will lose on average \$392,500 in lifetime earnings and \$175,000 in superannuation at age 67.³⁸ Some people who care for extended periods of time will lose substantially more, with the most affected 10% losing at least \$940,000 in lifetime income, and \$444,500 in retirement savings.³⁹ The report also found that lifetime earnings are reduced by \$39,600 for every year that someone is a primary carer, indicating that for many carers who have been caring from their mid-thirties or forties, there are significant lifetime impacts that may act as a key contributing factor in long term financial insecurity, inequity into retirement, and increases the risk of homelessness later in life.⁴⁰

For those on low incomes, including government income support such as Carer Payment, the rising cost of living presents significant financial challenges, with people in higher financial stress reporting that they have had to make increasingly difficult and frequent compromises, often choosing between medication, heating, and food.⁴¹ Carers NSW has also heard similar reports from carers who have suddenly needed to use charity services for food and clothing, or choose between heating and medication expenses. Carers NSW believes that investing in carer-focused measures aimed at

³⁶ Carers NSW (2022).

³⁷ Carers NSW (2020a).

³⁸ Evaluate (2022) *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*, available online at: <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>, viewed 25 August 2022.

³⁹ Evaluate (2022).

⁴⁰ Ibid.

⁴¹ NSW Council of Social Service (2022), *Tough Times, Hard Choices: Struggling households and the rising cost-of-living in NSW*. Available online at <https://www.ncoss.org.au/policy-advocacy/policy-research-publications/tough-times-hard-choices-struggling-households-and-the-rising-cost-of-living-in-nsw/>, viewed 04 November 2022.

addressing cost of living pressures will be key to ensuring the ongoing financial stability of carers and the people they care for in the coming Budget period.

Addressing barriers to participation in employment

A key contributing factor to financial stress among carers is the impact of caring responsibilities on economic participation. Carers NSW biennial Carer Surveys have consistently shown that carers often reduce their paid working hours or leave the workforce as a result of their caring responsibilities. Australian Bureau of Statistics 2018 data supports the fact that carers experience considerably worse employment outcomes than non-carers, with 52.2% of carers in employment compared with 75.9% of people without caring responsibilities.⁴²

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

- Carers NSW 2022 National Carer Survey respondent

Caring can have significant impacts on a carer's ability to participate in paid work and subsequent capacity to earn an income. Anyone can become a carer at any time, and carers are highly demographically diverse, as are the people for whom they care. Using data from Waves 2 to 4 of the Household Income and Labour Dynamics Australia (HILDA) survey 2001, it has been estimated that between 3–4% of Australian employees become carers each year.⁴³

Despite the impacts of caring on employment, many carers do participate in paid work. Participation in employment can have positive impacts for carers including increased financial security, social interaction and providing a sense of self outside of the caring role. Carers NSW 2022 National Carer Survey found that carers in paid employment reported better wellbeing and mental health.⁴⁴ Approximately 3 in 4 respondents in paid work (74.7%) reported that work provided important social connections outside of their caring role, and 82% reported that it gave them a sense of purpose. However, just over half of respondents (50.8%) had considered quitting in the past 6 months. Qualitative data from the Survey also suggested that while many carers felt that they had to work to meet their and a lack of time to themselves to rest or recuperate.

3 in 4
carers said paid
work provided
important social
connections



1 in 2

carers had recently
considered
quitting



In order for carers to participate in paid employment, carers are more likely to need flexibility within the workplace to enable them to balance work and care. They may be more likely to participate in casual work or to work across multiple employers to enable them to continue to care, and as a result often experience precarious working conditions that offer limited or no leave provisions, job security, or income protection. The *Tough Times, Hard Choices: Struggling households and the rising cost-of-living in NSW* report released by the NSW Council of Social Service (NCOSS) in 2022 found that of people

⁴² Australian Bureau of Statistics (ABS) (2019) *2018 Survey of Disability, Ageing and Carers, Summary findings*, available: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>, viewed 04 November 2022.

⁴³ Hill, T., Thomson, C., Bittmann, M. & Griffiths, M. (2008) What kinds of jobs help carers combine care and employment? *Family Matters*, 80, 27–32.

⁴⁴ Carers NSW (2022).

with 2 or more jobs, 25% were carers.⁴⁵ The report also found that in 2021-22, carers experienced significant negative changes to employment, with 39% of carers experiencing less job security, 16% having lost their job, and 40% having experienced reduced hours.⁴⁶

Where carers are unable to secure or maintain employment due to an increase in their caring responsibilities or an inability to access adequate workplace flexibility to sustain work and care, carers may take prolonged breaks from the workforce to enable them to continue to care. In many instances, their qualifications or skills may become outdated and they may need to reskill or retrain in a new industry to enable them to re-enter the workforce.

Recent Federal inquiries including the Select Committee on Work and Care and the Productivity Commission inquiry into Carer Leave, the Treasury Employment White Paper and the ongoing Federal inquiry into carer recognition have highlighted the need for greater investment and initiatives from governments to address the numerous and complex barriers to securing and maintaining employment experienced by carers. Carers NSW believes that the NSW Government has a number of opportunities to support carers to participate in economic activities through increased investment in carer-focused job readiness support for diverse and hidden carer groups, initiatives aimed at increasing the number and diversity of carer inclusive workplaces and support for young carers transitioning into higher education or employment.

Extending and expanding carer-focused employment initiatives in NSW

Carers NSW commends the NSW Government for its investment in various employment programs to support vulnerable groups, including carers. This includes investment by Regional NSW in the Young Carer Skills Project, Women NSW in the Return to Work Pathways Program and NSW DCJ in the ongoing delivery of the Carers + Employers program and development of a new Carers + Employment Hub. Carers NSW believes ongoing carer-focused job readiness and career support is needed to address the nuanced challenges experiences by carers in the employment context. However, Carers NSW has concerns that some of these programs are limited to certain carer cohorts or regions. Additionally, there is a need for ongoing investment in these, or similar initiatives to continue to address barriers to economic participation for carers.

Ongoing investment in carer inclusive workplaces

Recent Federal inquiries focusing on carer employment have highlighted the need for carer-inclusive workplace policy that provides support and flexibility that enables carers to sustainably balance care and work. Carers NSW Carers + Employers accreditation program enables employers to reflect on and update their policies and practices to ensure that they are operating in a carer inclusive way, achieving accreditation across three levels that demonstrates genuine commitment and action to improving awareness and support for carers within their organisation.

Carers NSW commends the NSW Government on the accreditation of six NSW Government agencies and departments through the Carers + Employers program, notably NSW Treasury and Regional NSW who recently achieved level 1 accreditation, the Department of Customer Services who achieved level 2 accreditation and the Department of Communities and Justice who renewed their level 2 accreditation. Carers NSW has also been supporting several agencies including Sydney Local Health District, Far West Local Health District and Transport for NSW to work towards accreditation or higher levels of accreditation.

⁴⁵ NSW Council of Social Service (2022), *Tough Times, Hard Choices: Struggling households and the rising cost-of-living in NSW*. Available online at <https://www.ncoss.org.au/policy-advocacy/policy-research-publications/tough-times-hard-choices-struggling-households-and-the-rising-cost-of-living-in-nsw/>.

⁴⁶ Ibid.

Accreditation of the NSW Government agencies through the Carers + Employers program demonstrates a genuine commitment of the NSW Government in championing carer-friendly workplace approaches and improving carer economic participation. Accreditation also supports NSW public service agencies to meet their obligations under the NSW *Carers (Recognition) Act 2010* to ensure that their human resources policies are developed with due regard to the NSW Carers Charter.

Carers + Employers is now in a strong position and is poised to grow. The funding to date has resulted in a robust national accreditation framework that can accommodate diverse employer types, a highly engaged network of employers that is motivated to share its enthusiasm for the project with others, and a range of professional collateral and program resources that add value for employers engaging with the project. Ongoing funding will enable the further refinement and expansion of the project, its network and its offerings, resulting in greater national awareness of the business case for supporting carers in the workplace and a more carer-friendly workforce overall.

During National Carers Week 2023, the Federal Minister for Social Services, The Hon Amanda Rishworth MP, announced the establishment of the new Federally funded Carer Inclusive Workplace Initiative, following through on a commitment made during the 2022 Jobs and Skills Summit. Carers NSW has been working closely with the Minister's office and Carers Australia to ensure that this initiative – which provides a light-touch approach through self-assessment only – complements, rather than duplicates, Carers + Employers and provides a pipeline through to accreditation, which offers more robust assessment and accountability through external review.

The ongoing commitment of the NSW Government to Carers + Employers through its embedding in the current ten-year NSW Carers Strategy is a strong reason for continued resourcing to deliver the program. Furthermore, the employers that have invested time and resources in becoming accredited and proceeding through the accreditation levels would be disappointed to have the recognition and support offered by the program discontinued.

Extending and expanding existing carer-focused employment initiatives

In addition to ensuring carer-inclusive workplaces across NSW, to support carers who may have left the workforce or be in jeopardy of leaving the workforce, carer-focused employment initiatives are needed to support carers to overcome complex and nuanced barriers to work and enable them to enter and remain in the workforce. A number of tools and resources to support carers to participate in employment already exist, however there has been no central location for carers to access employment information and resources. Under the NSW Carers Strategy 2nd Action Plan, Carers NSW is currently leading the development of a Carers + Employment Hub which will provide a centralised point of employment information, resources and supports for all carers. To ensure effectiveness of the Hub, Carers NSW believes there must be ongoing, sustainable investment in complementary tangible carer-focused employment and job-readiness support.

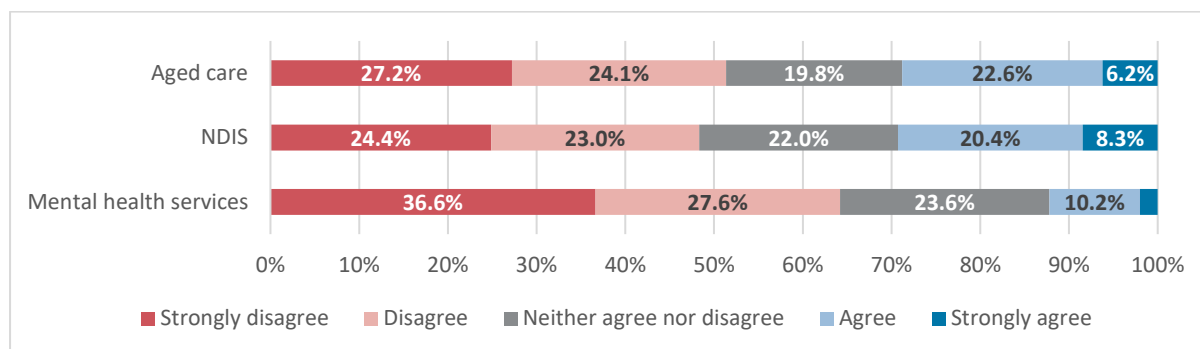
Carers NSW has welcomed recent investment by the NSW Government in carer-focused employment initiatives including the Young Skills Project and the Return to Work Pathways Program. These time-limited projects aim to address the nuanced and complex barriers to employment experienced by young carers and women carers by providing job-readiness support and streamlined pathways to employment. However, Carers NSW believes that there is a need for broader and longer-term investment in carer-focused employment projects that are inclusive of all carers.

In addition to practical job-readiness support with finding a job in the form of job seeking skills, coaching and mentoring, many carers will also require replacement care to enable them to participate in employment. The Carers NSW 2022 National Carer Survey⁴⁷ found that while some carers could access

⁴⁷ Carers NSW (2022).

adequate formal care services for the person they care for to enable them to participate in work, for many, formal care services did not enable them to work (Figure 6).

Figure 6. Services for the care recipient enabled carers to participate in paid work



Phase 3 of the Return to Work Program⁴⁸ provided one-off grants to assist women carers with costs associated with entering or re-entering employment, including replacement care or respite. Carers NSW has concerns that the Return to Work Program, which was intended to compliment the new Return to Work Pathways Program appears to have been discontinued. Carers NSW believes that investment by the NSW Government in initiatives that fund or facilitate respite or replacement care that enables carers to participate in paid work is vital to enabling carers to participate in employment where they cannot access this support through formal service systems.

Investing in targeted employment initiatives for hidden and diverse carer groups

Carers NSW acknowledges the NSW Government’s investment in programs and projects that provide targeted support to women carers and young carers to enter or re-enter the workforce. However, Carers NSW believes that there are further opportunities to expand on this investment to better support a broader range of carers in NSW to participate in economic activities.

While male carers are more likely to be in paid employment than women carers, male carers are twice as likely to be denied or experience stigma or exclusion when accessing flexible working arrangements in the context of their caring role⁴⁹ and as a result, some male carers may be required to retrain and seek work in different sectors, or leave the workforce altogether. Male carers also experience similar barriers to female carers when re-entering employment, especially where they may have had extended breaks from work to care. However, despite these challenges, at current, there is no carer-focused job readiness support available to male carers.

Within the diversity of caring experiences, barriers to economic participation are also more elevated for carers who may face additional structural barriers associated with their cultural background, sexuality, identification as Aboriginal and Torres Strait Islander or for carers with a disability. These diverse, often hidden carer groups are much more likely to be caring for others and less likely to identify as carers.

The *Gari Yala (Speak the Truth)* report⁵⁰ details concerning intersectional impacts of caring on Aboriginal and Torres Strait Islander female carers in the workplace. The report found that Aboriginal

⁴⁸ <https://www.service.nsw.gov.au/services/business-industries-and-employment/get-notified-about-return-work-phase-3>.

⁴⁹ Bain & Company (2016), *The power of flexibility: A key enabler to boost gender parity and employee engagement*; Diversity Council Australia (2021), *Inclusion@Work Index: Mapping the state of flex in the Australian workforce*. Available online at:

https://www.dca.org.au/sites/default/files/report_inclusionatworkmappingthestateofflex_20211012.pdf

⁵⁰ Evans, O. (2021) *Gari Yala (Speak the Truth): gendered insights, WGEA Commissioned Research Report in partnership with the Jumbunna Institute of Education and Research and Diversity Council Australia*, available online at: <https://www.wgea.gov.au/publications/gari-yala-speak-the-truth-gendered-insights>, viewed 25 august 2022.

and Torres Strait Islander female carers often experience a 'triple jeopardy' effect in the workplace due to the compounding effects of racial and gendered inequality, and disadvantage due to being a carer. As such, it was highlighted that Aboriginal and Torres Strait Islander female carers are a particularly vulnerable group, who are more likely to be in culturally unsafe and unsupported employment, especially in the context of balancing work and care.

Carers NSW encourages the NSW Government, in line with priority 4 of the NSW Carers Strategy, to increase and expand on investment in carer-focused employment initiatives and job-readiness support, with targeted investment in initiatives aimed at supporting diverse and hidden carer groups enter or remain in employment. To support access and uptake for these initiatives, Carers NSW believes that they could be effectively centralised within the new Carers + Employment Hub, currently in development by Carers NSW under the NSW Carers Strategy 2nd Action Plan.

Recommendations

- 3.1 Invest in continuing the Carers + Employers accreditation program
- 3.2 Extend and expand existing NSW Government funded job-readiness programs such as the Return to Work Pathways Program to be inclusive of all carers in NSW
- 3.3 Reinststate the Return to Work Program or explore alternative opportunities to address costs associated with entering or re-entering employment for carers, including replacement care, through small grants or financial packages
- 3.4 Invest in targeted employment and job-readiness support for diverse and hidden carer cohorts
- 3.5 Expand on employment supports for carers through the Carers + Employment Hub

Supporting young carer transitions into higher education and employment

In NSW, there are approximately 83,700 young carers who are up to the age of 25 years.⁵¹ This is likely an underestimate of the young carer population size, as many young carers do not identify as carers. This is often because they view the support that they provide as an intrinsic part of their role as a sibling, spouse, daughter/son, parent, relative or friend. Many others do not identify because they, or the people around them, do not know what a young carer is, or because they are afraid of the implications of disclosing their family situation, which could lead to stigma or bullying, or raise questions around child protection.⁵²

"It's even hard to articulate what I do day to day. Because it's quite normal if that makes sense?"

- Melina, aged 24, metropolitan Sydney
(Carers NSW, 2020b)

Young carers provide a range of practical, specialist and emotional assistance which often exceed community expectations of what a child or young person can and should be responsible for. This includes communication and systems navigation support in culturally and linguistically diverse families. Research on young carers in schooling demonstrates an association between caring responsibilities and reduced school attendance, engagement and performance and risk of long-term disadvantage.⁵³

⁵¹ ABS (2019).

⁵² Cass et al. (2011).

⁵³ Ibid.

Research indicates that young carers are at particular risk of disengagement from school and further education, and of reduced socio-economic participation over their life course. These outcomes result from the many barriers to successfully balancing caring responsibilities with paid work or study, and to accessing timely support. Young carers are more likely than many of their peers to live in households experiencing socio-economic disadvantage, and to experience compounding socio-economic disadvantage as they grow older. Research indicates that young carers are less likely to complete secondary school and obtain a post-secondary education,⁵⁴ and economic modelling by the Department of Social Services⁵⁵ concluded that young carers are at relatively high risk of lifetime welfare dependency.

Despite significant barriers to formal education and workforce participation, young carers display high levels of transferable skills between caring and work, including self-efficacy, life skills and maturity because of their caring role and responsibilities. Carers NSW research highlights that young carers commonly demonstrate high levels of patience, empathy, resilience, organisation, time management, confidence in public speaking and advocacy, and other professional skills.⁵⁶ These capabilities enable young carers to be readily able to engage and excel in professional settings with the appropriate supports.

Young carers are particularly vulnerable at transition points, such as transitioning out of high school into higher education or employment. Through these transitions, young carers may lose their established formal and informal supports who may be aware and understanding of their caring responsibilities and the way that this impacts on them. When entering new environments, young carers may need to identify the correct supports and go through the process of disclosing their caring role or providing evidence of this in order to access support or reasonable adjustments. They may also need to establish new friendships and repeatedly navigate conversations about their caring role in social settings or interactions.

While there are a number of services and supports to assist students to prepare for and complete the HSC, included targeted HSC preparedness workshops and tutoring services, Carers NSW consultation with young carers indicates that they are often unaware of these, or unable to access them due to the lack of time and financial resources at their disposal. Financial and academic supports for young carers do exist, but often struggle to identify and reach the young people most in need. Carers NSW believes there is an opportunity for the NSW Government to provide additional targeted support for young carers in years 11 and 12 to support them to complete their education and achieve optimal outcomes that enable them to pursue further education or employment in industries of their choice.

Additionally, Carers NSW believes there are also a number of opportunities to address barriers to employment for young carers entering the workforce. The Young Carer Skills Project, funded by Regional NSW is currently piloting approaches to improving support for young carers seeking to enter employment in the disability sector. Many young carers have suitable transferable skills from their caring role that they can apply to care work in the disability sector. The disability sector, especially in regional areas, has a high unmet workforce demand and may provide the flexibility to enable young carers to balance work with their caring role.

The project aims to encourage young carers who may be interested in entering care work to pursue these interests by supporting them to identify and overcome barriers to employment in the sector. This

⁵⁴ Hill, T et al. (2011), Young Carers: Location, Education and Employment Disadvantage, *Australian Journal of Labour Economics* (14;2), pp. 173-198.

⁵⁵ Department of Social Services (2016) TTL Fund Tranche 1: Priority group – Young carers, available online at: <https://engage.dss.gov.au/wp-content/uploads/2016/12/TTL-Fund-Tranche-1-Priority-Group-Data-Young-Carers-20161208.pdf>, viewed 10 November 2023.

⁵⁶ Carers NSW (2020b) *Young carer research project: Summary of findings*, available online at: https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_of_findings.pdf, viewed 2 March 2022.

includes meeting the costs of obtaining necessary pre-employment checks and vocational training such as first aid certificates, which are often financially unobtainable for young carers, and supporting young carers to obtain a drivers licence, often required for work in the care and support sector. Carers NSW believes continuing to expand on this project, as well as similar initiatives that address barriers and costs associated with entering employment for young carers is likely to support young carers to more successfully transition into employment and to achieve greater economic security across the lifespan.

Recommendations

- 3.6 Invest in programs to support young carers in their final years of high school to achieve optimal education outcomes and transition into further economic activities
- 3.7 Extend and expand on the Young Carer Skills Project to support more young carers to enter employment

CONCLUSION

This Pre-Budget Submission has highlighted 21 recommendations for the NSW Government to invest in improving the recognition, inclusion and support of carers in NSW, in line with its existing commitments under *NSW Carers (Recognition) Act 2010* and *NSW Carers Strategy: Caring in NSW, 2020 – 2030*. Carers NSW welcomes the increasing attention being paid to carers across the NSW Government and looks forward to continuing to work closely with its departments and agencies, as well as other external stakeholders, in progressing innovation and impact in a range of key areas.