

14 March 2025

Mental Health and Suicide Prevention Agreement Review
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Carers NSW welcomes the opportunity to provide a submission to the Productivity Commission in response to the Mental Health and Suicide Prevention Agreement (the Agreement) Review. Carers NSW commends the federal and state and territory governments on the establishment of the Agreement as a demonstrated commitment to improving the access to and adequacy, availability, appropriateness and effectiveness of mental health and suicide prevention services and supports. However, Carers NSW believes that the Review of the Agreement provides an opportunity to identify ongoing barriers to accessing mental health services and supports that could be better addressed through the Agreement, and to improve recognition and support for carers more broadly, as a group at increased risk of suicide due to the high level of psychological distress and other heightened risk factors often reported by carers.¹

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.

Thank you for accepting our submission. For further information, please contact Melissa Docker, Manager Policy and Development on (02) 9280 4744.

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

¹ Suicide Prevention Australia (2022) *Suicide among carers*, available online at: <https://www.suicidepreventionaustralia.org/wp-content/uploads/2022/10/SPA-Suicide-Among-Carers-Policy-Position-Statement-October-2022.pdf>, viewed 24 October 2024

Introduction

Carers NSW commends all levels of government on the establishment and implementation of the Mental Health and Suicide Prevention Agreement. The Agreement marks a significant commitment to a coordinated, whole of government approach to improving mental health and suicide prevention in Australia. While Carers NSW welcomes all initiatives aimed at improving access to services and supports aimed at responding to mental ill health and suicidality, Carers NSW believes that there remain significant opportunities to improve access to services and supports and ensure investment in targeted supports aimed at addressing the mental health and wellbeing impacts of caring for a family member or friend.

Identifying and responding to carers own mental health and suicide prevention needs

There are approximately 3 million family and friend carers in Australia, including 958,500 carers in NSW.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. It was estimated in 2020 that to replace the care provided by carers, it would cost governments more than \$77 billion each year.³

Given the significant impacts of caring on carers' own mental health and wellbeing, Carers NSW believes that there are opportunities within the Agreement and its evaluation to improve and increase support for all carers. Carers NSW believes that the current Agreement does not adequately acknowledge, aim to address or evaluate the effectiveness of services and supports in addressing the high levels of psychological distress reported by carers, which may place them at greater risk of self-harm and suicide.⁴

Many carers within NSW report concerning levels of psychological distress that may increase their risk of suicide. For example, an Australian study on carers of people living with dementia found that approximately 16% experienced thoughts of suicide more than once in the previous 12 months,⁵ demonstrating that the need to address carer suicidality more broadly.

The 2024 National Carer Survey⁶ found that more than half (53.3%) of respondents from NSW reported high/very high levels of psychological distress on the Kessler Psychological Distress Scale-5 (Kessler-5).⁷ Additionally, many NSW respondents reported a number of other concerning results in domains that may act as social determinants for self-harm and suicide including social inclusion, income and social protection, and housing and basic amenities.⁸ The Survey found that more than 3 in 5 (61.4%) respondents were socially isolated, more than half (59.5%) had had one financial stress experience in the past 12 months and more than 1 in 20 (6.3%) reported that they never or only sometimes had a safe place to live. High intensity and long duration of care can also compound the impacts of caring on carer health and wellbeing.

Carers are also overrepresented in cohort groups who experience higher risks of suicide, including Aboriginal and Torres Strait Islander communities, LGBTQI+ communities, culturally and linguistically

² Australian Bureau of Statistics (2024), *Disability, Ageing and Carers, Australia: Summary of findings, 2022*, New South Wales Tables, Canberra.

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

⁴ Suicide Prevention Australia (2022).

⁵ O'Dwyer, S.T., Moyle, W., Zimmer-Gembeck, M. & De Leo, D. (2016) Suicidal ideation in family carers of people with dementia, *Journal of Aging Mental Health*, 20(2), available online at: <https://pubmed.ncbi.nlm.nih.gov/26161825/>, viewed 24 October 2024.

⁶ Carers NSW (2024a) 2024 National Carer Survey, NSW highlights, available online at: https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carer-Survey/2024-National-Carer-Survey_NSW.pdf, viewed 24 October 2024.

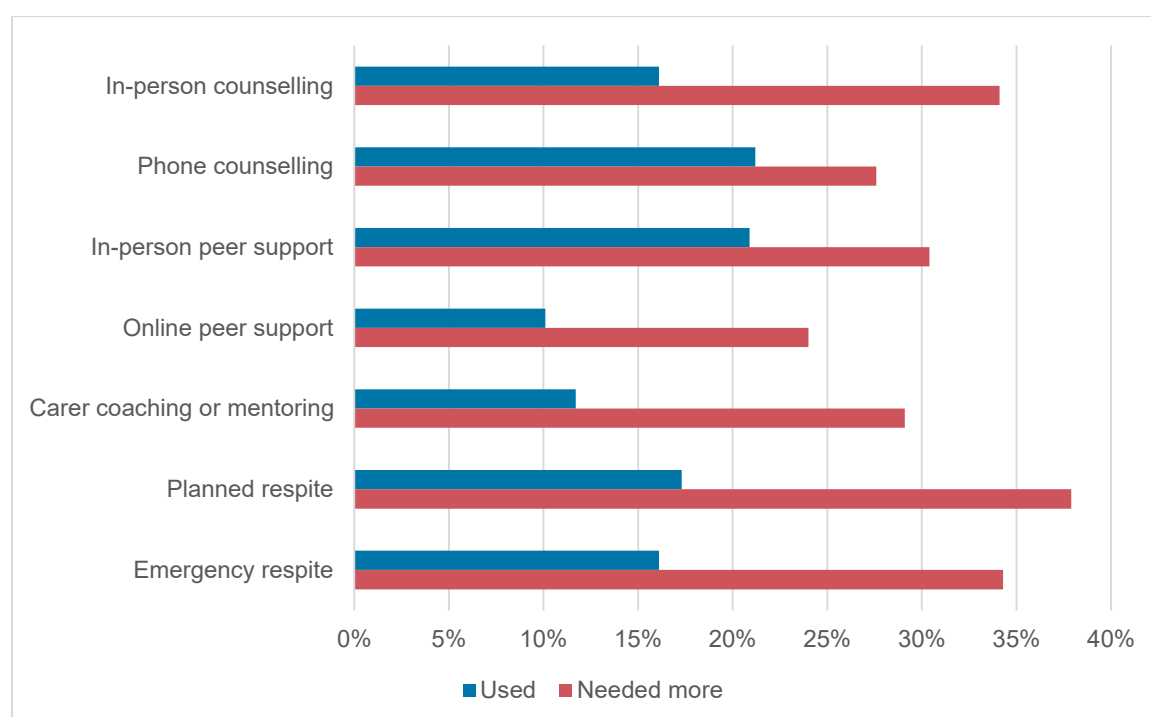
⁷ Carers NSW (2024a).

⁸ Consultation draft

diverse (CALD) communities, people living with disability and people living in rural, regional and remote areas. A recent study also found that young carers providing support with core care tasks, such as providing personal care, assistance with toileting, mobility or communication, may also be at higher risk of self-harm or suicide than other young people.⁹

The Carers NSW 2024 National Carer Survey¹⁰ also found that many respondents were unable to access support with their own needs at the level needed (Figure 1). While some carers were accessing in-person and telephone counselling, 34.1% and 27.6% reported needing more of these services respectively.¹¹ These findings were consistent with the Parliamentary inquiry into the recognition of unpaid carers, which recommended that the Australian Government explore how to increase access to high-quality counselling and mental health support options for a diverse range of carers.¹²

Figure 1. Carers' access to carer support services¹³



While Carers NSW recognises the Australian Government's commitment to improving access to mental health supports through increased access to the range and availability of carer counselling available through Carer Gateway, as outlined in the National Carer Strategy Action Plan. Results from the Carers NSW 2022 and 2024 National Carer Surveys indicate that carer mental health and wellbeing outcomes, as well as outcomes on associated domains, continue to decline (Table 1). As such, Carers NSW believes that greater bipartisan investment and accountability is needed to ensure that carers are adequately supported to achieve optimal mental health and wellbeing outcomes themselves.

⁹ King, T., Redmond, G., Reavley, N., Hamilton, M. and Barr, A (2023) *Prospective Study of Suicide and Self-Harm Among Young Carers Using an Australian Cohort*. Available online at: <http://dx.doi.org/10.2139/ssrn.4578556>, viewed 24 October 2024.

¹⁰ This data is not yet available for the 2024 National Carer Survey as the findings are still being analysed.

¹¹ Carers NSW (2024b) *2022 National Carer Survey, unpublished data*.

¹² Parliament of NSW, Standing Committee on Social Policy and Legal Affairs (2023) *Recognising, valuing and supporting unpaid carers*, available online at:

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Social_Policy_and_Legal_Affairs/UnpaidCarers/Recognising_valuing_and_supporting_unpaid_carers, viewed 25 October 2024.

¹³ Carers NSW (2024b).

Table 1: Distress, wellbeing, and social connectedness in the Carers NSW National Carer Surveys, 2022 to 2024 (NSW respondents)

	2022 National Carer Survey	2024 National Carer Survey
Carers reporting high/very high psychological distress (Kessler 5)	44.9%	53.3%
Average wellbeing score (PWI, % of scale maximum)	57.6%	55.3%
Carers reporting being socially isolated or highly socially isolated	52.7%	61.4%
Carers reporting at least one experience of financial stress	55.7%	59.5%

Furthermore, in regard to evaluation of the effectiveness of targeted carer mental health initiatives, policies and programs, Carers NSW believes there are a number of opportunities to better measure and monitor carer mental health outcomes that could complement existing mechanisms. Carers NSW believes that the evaluation of Carer Gateway services focused on carers mental health needs should be evaluated at the point of service, using outcome measure tools such as the Kessler-10 to ensure appropriate and thorough evaluation of the effectiveness of these services. Current evaluation methods may not be appropriate or sensitive enough to capture and evaluate the effectiveness of these services. Furthermore, ensuring carer variables are included in key population level surveys and research that include mental health variables and that data linkages are utilised to provide insights into carer mental health experiences, outcomes and changes over time is likely to support improved evaluation of whole-of-government policies and approaches. Consistent reporting of carer suicides and suicidality will also support understanding of the prevalence and extent of suicide and suicidality amongst carers, and enable exploration of risk factors and prevention strategies to inform future initiatives and investment.

Carers NSW believes that based on the findings of the inquiry into carer recognition¹⁴ and in line with recommendations from Suicide Prevention Australia,¹⁵ there are a number of opportunities to strengthen the Agreement in relation to supporting optimal carer mental health outcomes. Opportunities include identifying carers as a priority cohort, initiatives aimed at understanding of carer suicidality and coordinated investment in targeted mental health suicide prevention support for carers.

Improving outcomes for mental health carers

Data from the ABS indicates there are approximately 50,000 mental health carers in NSW,¹⁶ people who provide unpaid care or support to a family member or friend living with mental illness or psychosocial disability, though this number is estimated to be much higher. While not everyone living with mental health conditions, mental illness or psychosocial disability receives informal support or would identify with having a 'carer'. However, family members and friends are often important in the

¹⁴ Standing Committee on Social Policy and Legal Affairs (2024) *Recognising, valuing and supporting unpaid carers*, available online at: https://parlinfo.aph.gov.au/parlInfo/download/committees/reportrep/RB000193/toc_pdf/Recognising_valuingandsupportingunpaidcarers.pdf.

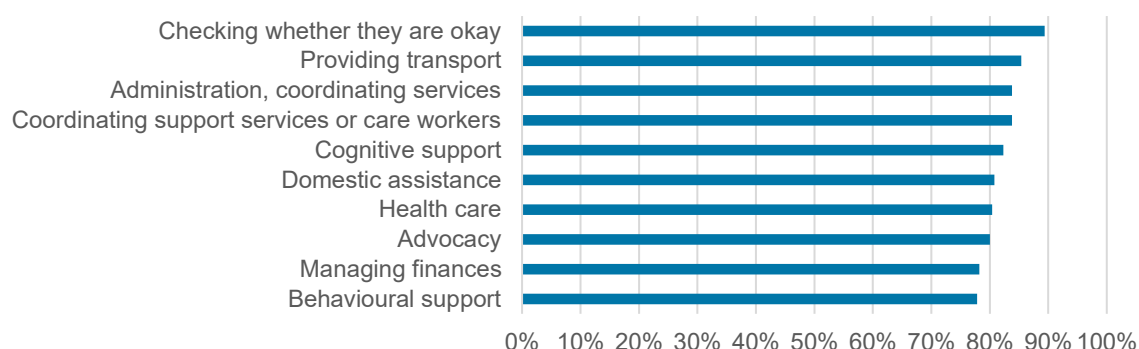
¹⁵ Suicide Prevention Australia (2022) *Suicide among carers*, available online at: <https://www.suicidepreventionaustralia.org/wp-content/uploads/2022/10/SPA-Suicide-Among-Carers-Policy-Position-Statement-October-2022.pdf>, viewed 24 October 2024

¹⁶ ABS (2022) National Study of Mental Health and Wellbeing. Available online at: <https://www.abs.gov.au/statistics/health/mental-health/national-study-mental-health-and-wellbeing/latest-release>.

lives of all Australians and can be essential members of care teams, providing support and enabling recovery.

Findings from the Carers NSW 2024 National Carer Survey also show that carers of people accessing mental health services in NSW report relatively high intensity caring roles. Most respondents (59.3%) reported providing care for over 60 hours a week, with more than 2 in 5 (43.7%) providing 24/7 care.¹⁷ A majority of carers reported providing a range of supports including physical, emotional and administrative supports (Figure 2). The high intensity of these caring roles often has significant emotional, physical and financial impacts on carers themselves, adversely affecting their health and wellbeing. While carers' health and wellbeing consistently measure lower than the general population,¹⁸ there is also evidence that carers of people living with mental illness are at greater risk of poor mental health outcomes than other carers.¹⁹

Figure 2. Care tasks performed by carers of people accessing mental health services in NSW

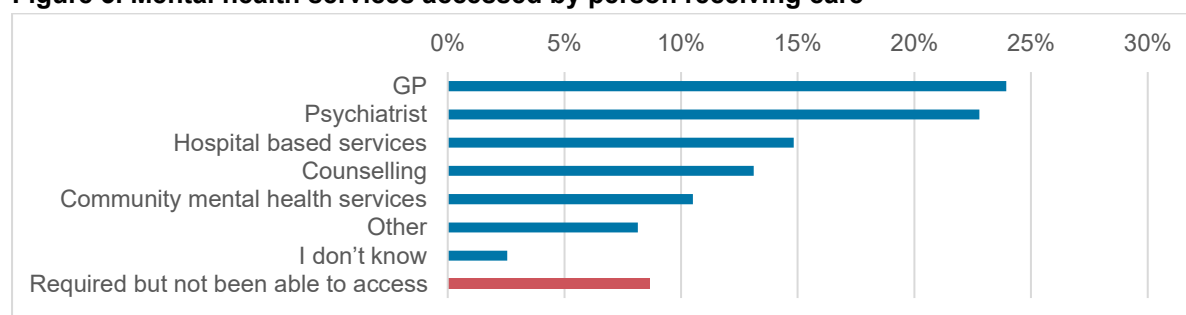


While the National Mental Health and Suicide Prevention Agreement does place some emphasis on the need to consult with carers as supporters within mental health and suicide prevention services, supports and initiatives, Carers NSW believes that a much greater focus on the roles and experiences of carers is needed. This will ensure that carers are adequately recognised, and that their experiences and needs are considered and met in the design and delivery of mental health and suicide prevention policy and programs.

Improving access to mental health, suicide prevention and aftercare services in NSW

Access to adequate mental health services remains an ongoing challenge in NSW. Of NSW respondents to the 2024 National Carer Survey, 795 (41.6%) were caring for someone accessing mental health services (Figure 2). Additionally, 136 (8.7%) reported that the person they cared for required mental health services but was unable to access them.

Figure 3. Mental health services accessed by person receiving care*



*Some carers were supporting someone accessing multiple mental health service types

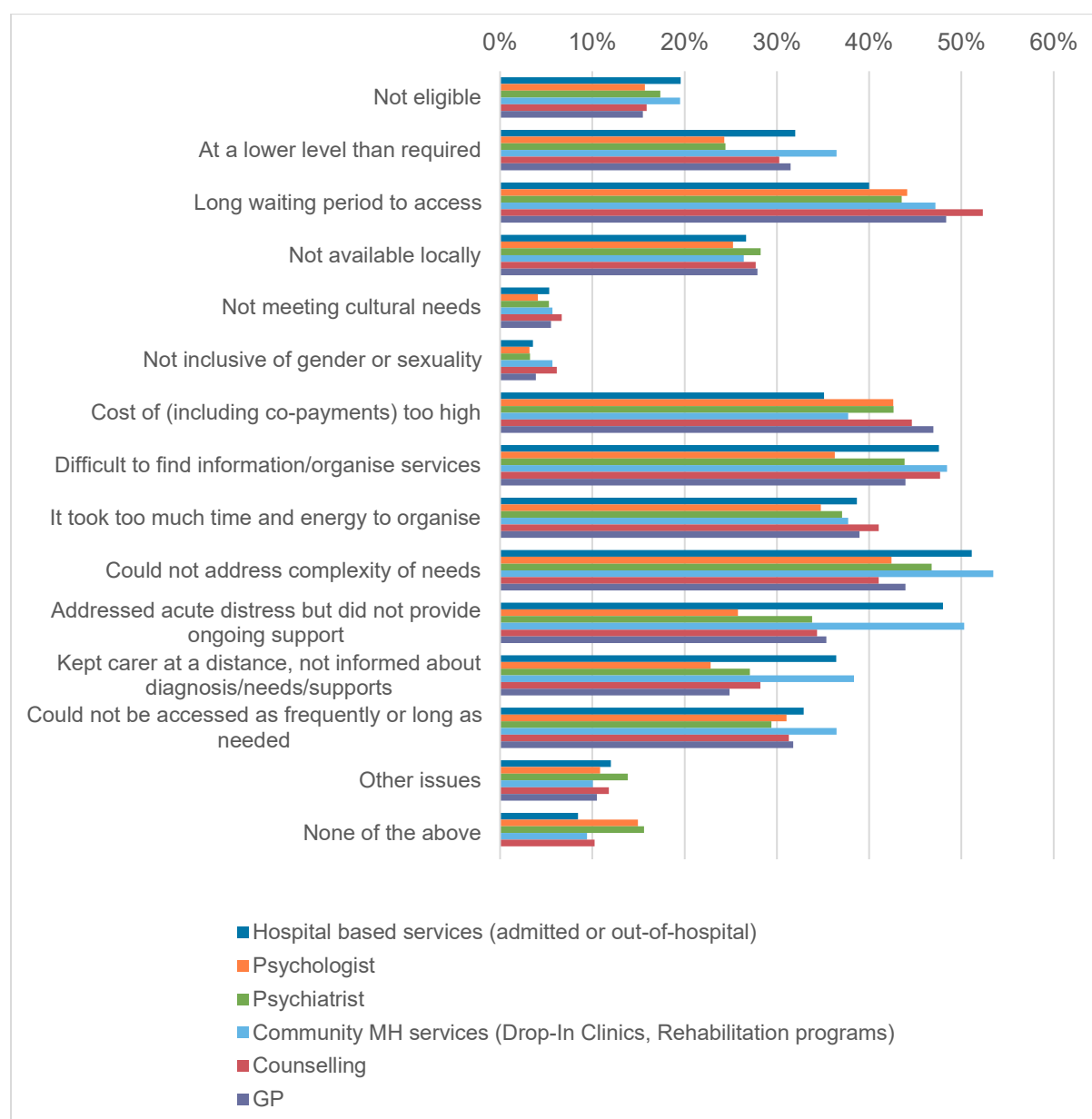
¹⁷ Carers NSW (2024)

¹⁸ ABS (2024).

¹⁹ Ibid.

Despite a number of new initiatives aimed at supporting people to access mental health services when and where they need them, carers continue to report significant barriers to accessing mental health services and supports (Figure 2). The 2024 National Carer Survey found that more than 40% of respondents supporting someone to access mental health services reported long wait times and that services could not address the complexity of needs across all service types. Additionally, more than 1 in 3 reported that the costs were too high, it was difficult to find information and organise services, and/or it took too much time and energy to organise services. Only a small percentage of respondents (10-15%) reported no challenges accessing mental health services.

Figure 4. Challenges experienced by carers supporting someone accessing mental health services



It is also important to note that within NSW, recent industrial action within the mental health sector, initiated since the 2024 National Carer Survey was conducted, has likely further reduced access to public psychiatric services in NSW.

Where people are unable to access mental health services and supports that adequately meet their needs, additional strain may be placed on carers to meet their needs or identify and navigate alternate

pathways to support. This additional caring load may further compound the impacts of caring on carers own mental health and wellbeing outcomes.

Carers NSW believes that findings indicate that the existing Agreement, while likely improving access to supports, is still not adequately meeting the need within NSW. Carers NSW believes that in order to address this and minimise potential impacts on carers, there is a need for even greater investment in mental health services and supports across all levels of government. This investment should focus on reducing wait times, ensuring that services are available at the level required and can address complex needs, and improving information, support pathways and service navigation to reduce administrative burden on carers.

Increasing targeted supports for mental health carers

Findings from inquiries into the mental health sector have continued to demonstrate the often-critical role carers play in the care and support of a family member or friend living with mental illness. The NSW Parliamentary inquiry into the equity, accessibility and appropriate delivery of outpatient and community health care in New South Wales (the Parliamentary Inquiry)²⁰ and the NSW Health-led gaps analysis into NSW Community Mental Health Services²¹ have made similar observations about the role and support of carers, as well as citing their need for carers to be appropriately recognised and included at critical points of engagement in the system. Further recommendations made in the Parliamentary Inquiry final report indicate the clear need for carers to receive dedicated resources, particularly regarding carer education, and supports, including respite services.²²

While Carers NSW has been encouraged to see in-principle support for carer education and respite,²³ to Carers NSW knowledge there has been no new programs or funding in NSW committed to increasing practical and emotional support for mental health carers. Though the state and federal governments currently fund services aimed at providing direct support to mental health carers in NSW, including targeted education, system navigation and advocacy, as well as emotional and practical supports available to all carers through Carer Gateway, findings from the Parliamentary Inquiry suggest that further investment is needed to ensure that all mental health carers can access the variety and level of supports that meet their needs.

Furthermore, data from the Carers NSW 2024 National Carer Survey indicates carers of people accessing mental health services still experience barriers to inclusion and support when engaging with the system. Figure 5 demonstrates how carers of people accessing mental health services who responded to the Survey do not always feel recognised for their caring role or are adequately included at important points of contact with the mental health system.

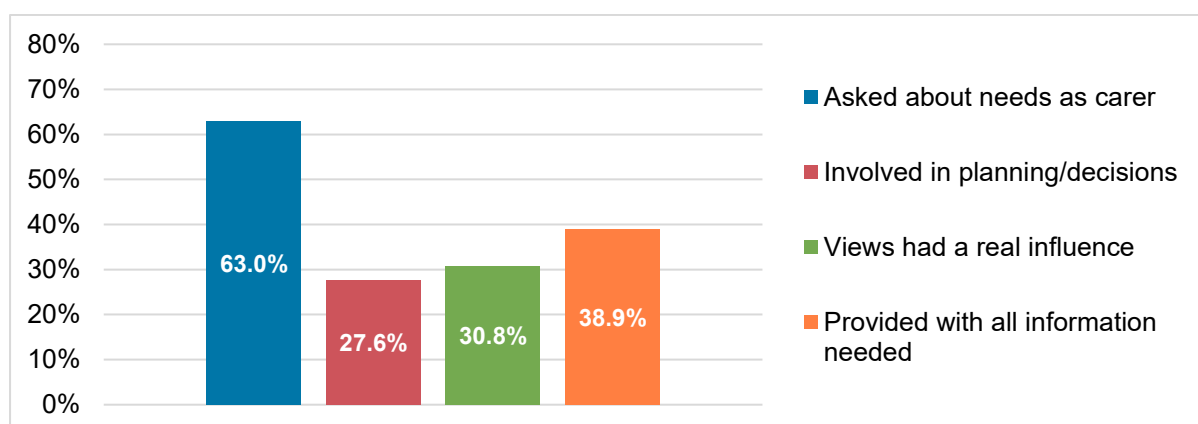
²⁰ NSW Legislative Council, Portfolio Committee 2. (2024) Report 64: Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales, available online at: <https://www.parliament.nsw.gov.au/lcdocs/inquiries/2973/Report%20No.%2064%20-%20PC2%20-%20Equity,%20accessibility%20and%20appropriate%20delivery%20of%20outpatient%20and%20community%20mental%20health%20care%20in%20NSW.pdf>, viewed 10 October 2024.

²¹ NSW Health (2023) NSW Community Mental Health Services Priority Issues Paper, available online at: <https://www.health.nsw.gov.au/mentalhealth/Documents/gap-analysis-report.pdf>, viewed 10 October 2024.

²² NSW Legislative Council, Portfolio Committee 2. (2024).

²³ NSW Government (2024) Government response – Report No 64 – PC2 - Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales, available online at: <https://www.parliament.nsw.gov.au/lcdocs/inquiries/2973/Report%20No.%2064%20-%20PC2%20-%20Equity,%20accessibility%20and%20appropriate%20delivery%20of%20outpatient%20and%20community%20mental%20health%20care%20in%20NSW.pdf>, viewed 10 October 2024.

Figure 5. Carer experiences engaging mental health services, disagreement with statements



To better equip carers to support a person accessing mental health services engage with and navigate the system, Carers NSW believes the Australian and NSW Governments should commit to additional investment in education, capacity building programs and service navigation support to complement existing information and support available for carers.

In addition to greater education, the Parliamentary Inquiry into mental health²⁴ highlighted a need for greater access to respite for mental health carers. While the NSW Government response to the inquiry²⁵ noted that Carer Gateway is responsible for respite for all carers, limitations of the Carer Gateway service model affect access to ongoing respite for carers and may also not be able to meet mental health carers' unique respite needs. Unlike other carers, respite for mental health carers often does not involve organising formal replacement care for the person they care for to enable them to take a break. Instead, mental health carers report a preference for respite opportunities that enable them to attend social or recreational activities outside of the home or caring arrangement with carer peers.

Carers NSW believes that as such, greater commitment from state and federal governments is needed to explore and investing in additional respite options that better reflect and meet the needs of mental health carers. Investing in additional education and respite for carers also aligns with the commitments of the Australian and NSW Governments through the National and NSW Carers Strategies.

"I would like to be in direct touch with someone to advise me on the difficulties of mental health caring and also avenues of contact for my own health, wellbeing and safety."

"[I would like the] ability to go away for a break but am unable to successfully do this due to my son's mental health and anxiety."

"I work full time to support my two children both of whom have substantial mental health challenges. Carer support programs in my area are held midday on a Tuesday. This means I cannot participate in trainings or support programs in person. Evenings are when I need to be available for my children; the last thing I have energy for is an online training session or a get-together with other carers."

- Carers NSW 2024 National Carer Survey respondents

²⁴ NSW Legislative Council, Portfolio Committee 2. (2024).

²⁵ NSW Government (2024).

The Mental Health Respite: Carer Support (MHR:CS) Program, previously funded by the Australian Government, provided mental health carers with preferred respite options. In 2019, during a period of significant reform, this program ceased, with funds for this program transferred to Carer Gateway. However, many mental health carers in NSW care for someone who is ineligible for or has opted out of accessing the NDIS, and Carer Gateway is unable to provide equivalent supports. Additionally, for carers seeking more traditional forms of respite, such as residential care, this often cannot be funded through Carer Gateway as funding required for these programs exceeds that available to carers at a federal level.

As such, Carers NSW believes that the NSW Government must conduct a review of unmet carer respite needs in the mental health sector and invest in additional programs or supports that ensure that carers can access respite options appropriate to their preferences and needs.

Luke has severe depression and lives with his mother Jo*. Jo was previously able to access support through the Mental Health Respite: Carer Support program. However, when it came time for that program to transition to the NDIS in their area, Luke was reluctant to access the NDIS. He refused to seek formal assistance or acknowledge that there was an issue. As a result, neither Jo nor Luke have access to support.*

*Names changed

Conclusion

Carers NSW again thanks the Productivity Commission for the opportunity to provide an initial submission in response to the Mental Health and Suicide Prevention Agreement Review. Carers NSW acknowledges the significance of the Agreement as a commitment of both federal and state and territory governments to improving access to mental health and suicide prevention, intervention and aftercare supports for all Australians and their families, carers and kin. However, Carers NSW believes that there remains a number of opportunities to continue to improve mental health and suicide prevention policies, programs and projects to reduce strain on carers to fill service gaps and to better understand and respond to carers own mental health needs.