

Submission
No 56

**INQUIRY INTO EQUITY, ACCESSIBILITY AND
APPROPRIATE DELIVERY OF OUTPATIENT AND
COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH
WALES**

Organisation: Carers NSW
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Portfolio Committee No. 2 – Health
NSW Parliament House
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Submission to the Portfolio Committee No. 2 - Health inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales

Carers NSW welcomes the opportunity to provide a submission to the Portfolio Committee No.2 - Health inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales. This submission will highlight the need to expand and improve outpatient and mental health care services in NSW to support the health and wellbeing of family and friend carers and the people they care for, and ultimately the sustainability of informal caring arrangements.

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 Jade Alexander, Policy and Development Officer

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW welcomes the opportunity to provide a submission to the Portfolio Committee No.2 - Health inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales and commends the NSW Government for investigating and working to improve the lives of people with mental illness and their carers. This submission details the need for increased outpatient and community mental health service availability and the strengthening of such services to be more carer-aware and carer-inclusive to improve outcomes for both people living with mental illness and their carers.

Caring for someone accessing mental health services in NSW

The National Study of Mental Health and Wellbeing conducted in 2021 by the Australian Bureau of Statistics found that an estimated 2 in 5 (44%) Australians aged 16–85 had experienced a mental disorder during their lifetime, and 1 in 5 (21%) Australians aged 16–85 experienced a mental disorder in the previous 12 months.¹

While not all people living with mental illness have or would identify as having a carer, for those who do, carers often play a pivotal role in supporting their family member or friend. The Carers NSW 2022 National Carer Survey found that respondents who were carers of people using mental health services² in NSW (n=568), 82.1% helped coordinate support services or care workers, 98.7% provided emotional support, 67.8% help with therapeutic activities (including mental health exercises), 82.7% advocated for the person they care for, and 83.4% provided social support such as helping them engage in relationships and in the community.³ Additionally, 94.4% of carers of people using mental health services in NSW reported that they check on the person they care for to see if they are okay.⁴

Data from the 2022 National Carer Survey revealed that carers of people using mental health services in NSW were most commonly caring for a child (including adult children) (60.8%), followed by a partner (30.4%), and a parent (17.5%).⁵ The age of care recipients varied significantly, with 24.9% aged 18 or younger, and 57.3% aged between 18 and 64 years old, and 37% aged 65 years and older.⁶ Over half of carers of people using mental health services (51.4%) reported that they were caring for a person with mental illness, 33.4% were caring for a person living with autism spectrum disorder (ASD) and 36.4% were caring for a person living with physical disability.⁷

2022 National Carer Survey data also revealed that that carers of people accessing mental health services in NSW reported high intensity caring roles. Most respondents (60.3%) provided care for 40 hours a week or more, with an average of 89 hours a week spent caring per week.⁸ The high intensity of these caring roles often has significant mental, physical and financial impacts on carers themselves, resulting in reduced overall health and wellbeing.

¹ Australian Bureau of Statistics (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>

² Carers of people using mental health services refers to carers who responded to the Carers NSW 2022 National Carer Survey who are caring for a family member or friend who accessed mental health services. Such carers may, therefore, be caring for people with a mental health condition, or who may have comorbidities and require mental health support in addition to support for other conditions such as autism spectrum syndrome or a physical disability.

³ Carers NSW (2022) National Carer Survey.

⁴ Ibid.

⁵ Ibid.

⁶ Ibid.

⁷ Ibid.

⁸ Ibid.

Improving access to outpatient and community mental health services in NSW

Carers of people using mental health services in NSW who responded to the 2022 National Carer Survey indicated that the person they care for accessed private psychologist, psychiatrist, or neurologist services (71.3%), mental health care through their GP (47.2%), counselling (25.7%), and community mental health services (18.7%). Concerningly, the Survey also found that just over 1 in 10 (11.8%) respondents reported that the person they care for was not able to access mental health services they need in NSW.⁹

Carers report a number of barriers to accessing mental health services in the community. In the 2022 National Carer Survey carers of people using mental health services in NSW reported that there were long waiting periods to access services (39.2%), the services required were not available locally (26.2%), and the cost of services (including co-payments) was too high (28.4%). When the person they care for was able to access mental health services, additional concerns arose, including that the service received was at a lower level than required (24.9%) and the service addressed mental distress but did not help with any of the causes (28.8%). These findings indicate that while service availability is a central concern, additional resources and supports are needed to ensure that the services that are available are suitable, effective, affordable, and accessible. Where individuals are unable to access the mental health service supports that they need, there is often an overreliance on carers to fill gaps in care, resulting in more prolonged and intense caring roles.

Carers NSW is also concerned by the disparity in outpatient and community mental health services available between metropolitan and rural, regional and remote locations. While there are gaps in mental health support services more generally, approximately 41% of respondents caring for people using mental health services live outside of metropolitan areas, 12% of whom were aged 15-24.¹⁰ Regional, rural and remote communities face a range of additional challenges due to their distance from key services and employment opportunities. As a result of service gaps and an overburdened mental health system, carers living outside metropolitan areas can experience additional barriers to participation and support as a result of increased caring responsibilities. Such carers also often have poorer health and wellbeing compared to non-metropolitan carers, and this is attributed to factors including the lack of services such as respite, increased isolation, and the tendency for such carers to have fewer informal networks to provide additional support.¹¹

Furthermore, with increasing demand and limited availability of outpatient and community mental health services, it is important to ensure integration with and capacity building of mainstream services such as justice or first responders who may be increasingly engaging with people living with mental illness and their carers. This is key to ensuring appropriate and timely support for people in crisis situations and preventing exacerbated mental health outcomes.

Improving carer recognition and inclusion in mental health services

Carer recognition legislation in NSW creates obligations for public sector agencies and human services agencies, including public health services, to recognise and include carers. The NSW *Carers (Recognition) Act 2010* (the Act), Schedule 1(c) states that 'Carers' unique knowledge and experience should be acknowledged and recognised', while Schedule 4 recognises carers as partners in care, stating at 4(a) that 'The choices, views and needs of carers and of the people they care for should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for'.¹² In addition to the principles outlined in the Act, the NSW *Mental Health Act 2007* also

⁹ Carers NSW (2022).

¹⁰ Productivity Commission (2019), *Mental Health, draft report*, Productivity Commission, Canberra.

¹¹ Winterton, R. and Warburton, J. (2011), 'Models of care for socially isolated older rural carers: barriers and implications', *Rural and Remote Health* (online) vol. 11, no. 1678.

¹² NSW *Carers (Recognition) Act 2010*

creates clear, legally enforceable requirements to identify and include carers in treatment planning and decisions.¹³ However, despite these legal obligations, many carers of people using mental health services report a lack of recognition as partners in care and inadequate information sharing by health professionals, which can increase the risks of harm to themselves and the person they care for, especially following discharge from acute mental health services when they are likely to be engaged with outpatient and community mental health services.

The Carers NSW 2022 National Carer Survey found that of respondents in NSW who care for people using mental health services, more than 1 in 3 (36.7%) disagreed that they were provided with all the information they needed to provide care and 1 in 4 (28.8%) disagreed that they were involved in treatment discussion and planning. Withholding information from carers that has direct application to their caring role may negatively impact on the quality and sustainability of care provided and can increase the patient's risk of medication non-compliance and readmission. A lack of appropriate and ethical information sharing may also have a detrimental impact on care recipient outcomes, particularly with regards to physical and mental health, safety in the community, medication compliance, behaviour needs and potential relapse, and may result in serious safeguarding risk.

"Hospital and community mental health were impossible to communicate with, left me out of decisions even when my brother did not have capacity to make decisions, and repeatedly ignored or blocked my attempts to communicate despite having consent and my name on file for many years."

- 2022 National Carer Survey respondent

As per the NSW *Carers (Recognition) Act 2010* and the NSW *Mental Health Act 2007*, Carers NSW believes that carer recognition and inclusion in outpatient and community mental health services must be strengthened. Carers NSW believes that increased carer awareness training may support improved identification and support of carers within the mental health setting. Additionally, the development of formal guidance for mental health professionals on identifying, including and supporting carers may also support more carer-inclusive responses.

Supporting carers own mental health

Due to the intensive nature of their caring role, carers of people using mental health services often experience poor mental health themselves. National data indicates that a quarter of all carers experience high or very high levels of distress, and are therefore highly likely to have a moderate to severe mental disorder.¹⁴ A further quarter of all carers experience moderate levels of distress;¹⁵ these figures are significantly higher than the general population. Additionally, there is evidence that carers of people living with mental illness are at greater risk of poor mental health outcomes than other carers.¹⁶

Supporting someone who is living with mental illness can be episodic, uncertain, and unpredictable. Like all carers, carers of people using mental health services may experience financial stress, strained relationships, and emotional distress, but are likely to also experience exacerbated challenges specific to their caring situation, including social stigma. Managing symptomatic behaviour can be challenging for carers and exclusion from treatment planning of the person they care for due to privacy and confidentiality concerns often exacerbates existing challenges. As a result of these challenges and their impacts on a carer's own mental health, carers of people living with mental illness may also be more

¹³ In Section 68, 'Principles for care and treatment', the Act stipulates that: (j) the role of carers for people with a mental illness or mental disorder and their rights under this Act to be kept informed, to be involved and to have information provided by them considered, should be given effect¹³.

¹⁴ Australian Bureau of Statistics. (2019). *Survey of Ageing, Disability and Carers 2018*. TableBuilder Dataset. Canberra: Australian Government. Available online at: www.abs.gov.au.

¹⁵ Ibid.

¹⁶ Ibid.

likely to access higher acuity mental health services themselves, such as outpatient or community mental health services.

Carers NSW believes that given the mental health impacts of caring, mental health services must be adequately equipped to recognise any carers that they may be supporting. Furthermore, it is imperative that mental health professionals within these services have an understanding of the nuances and complexities of caring for a family member or friend, and the implications of this on a carers' mental health to ensure that treatment and support can be tailored to carers' unique experiences and needs. Supporting carers to maintain their own health and wellbeing is key for ensuring the sustainability of informal caring arrangements.

Conclusion

Carers NSW thanks the Committee for the opportunity to provide feedback to improve outpatient and community mental health care in New South Wales. Carers NSW supports actions to address service gaps and expand recovery-oriented services and support to address the overreliance on informal carers in the community mental health setting. Furthermore, Carers NSW also believes that increased recognition and inclusion of carers within outpatient and community mental health services, including greater transparency and adequate information sharing, is needed to support the sustainability of the caring relationships and enable optimal outcomes for carers and the people they care for.