

# 2025 – 2026 Pre-Budget Submission

## Mental Health Carers NSW



**December 16, 2024**

Mental Health Carers NSW  
*Policy and Advocacy Team*  
*Disability Futures Advocacy Project Team*



**Mental Health  
Carers NSW**

## About Mental Health Carers NSW

As the peak body for mental health carers in NSW, MHCN represents the interests of mental health carers to the NSW Ministry of Health, and provides information, capacity development and systemic advocacy on behalf of mental health carers. It regularly consults with carers across NSW to gain information on their opinions and experiences with the mental health system. MHCN uses the information gained in these consultations to provide feedback on policies and services on behalf of carers to NSW Health and to other health services and policy makers. With its core functions funded by the Mental Health Branch of NSW Health, MHCN developed the Mental Health Carer Advocacy Network (MHCAN) to broaden its engagement with mental health carers in its advocacy and to assist roll out of the NSW Lived Experience Framework.

By influencing changes in policy, legislation, and service provision, MHCN aims to make a positive difference to the mental health system for carers and through the MHCAN to empower carers to become champions for change, sharing their lived experience to evoke the solidarity of humanity to promote mental health reform. Currently, MHCN consults, advocates and co-designs projects with families and carers through convenorship of the *Carers of Forensic and Corrections Patients Network* monthly meetings in collaboration with the Family and Carer Consultant, Justice Health and Forensic Mental Health Network, and the *Mental Health Carer Connection* monthly meetings.

In October 2022, MHCN was awarded the tender for Department of Communities and Justice Disability Advocacy Futures Program (DAFP) for psychosocial disability systemic advocacy. MHCN will deliver systemic advocacy through this project that includes liaising with Individual Advocacy Providers, stakeholders, government, and non-government decision-makers, and DCJ to improve understanding of the unique issues faced by people with psychosocial disability.

# Introduction

This submission provides recommendations for funding and investment by the NSW State Government in areas to support mental health carers and the person they care for. While carers are highly resilient, they may experience their own mental health issues because of deficits in the mental health system. The lack of psychosocial, financial and other supports for carers can result in carers experiencing significant stress and low wellbeing, and severe financial challenges. Similarly, MHCN is also concerned for the wellbeing of persons impacted by psychosocial disability. We recognise that the fluctuating and episodic nature of mental ill health can increase vulnerability to social isolation, loneliness, homelessness and other distressing circumstances for both carers and the people to whom they provide care.

Significantly greater investment is needed by the State Government to fund carer supports, including respite directly for mental health carers and raise awareness of such supports. The *2024 Inquiry into Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales* by Portfolio Committee No. 2 – Health, NSW Legislative Council recommended: ‘That NSW Government ensure funding for carer education, supports and resources, including respite services.’ (Recommendation 3).

MHCN is of the view that funding and investment by the NSW Government for the following is a critical need for carers and the person they care for, which if not addressed will continue to pose serious challenges to their health and wellbeing:

1. Carer education, supports, and resources, including respite services.
2. Recognition of carers through a ‘NSW Carer Card’.
3. Peer delivered carer service navigation and advocacy supports for carers of forensic and corrections patients.
4. Address Housing and Homelessness.
5. Invest in the community sector, advocacy and representation.

These supports include the employment of Carer Peer workers in NSW through the Family and Carer Mental Health (FCMHP); and additional funds for the FCMHP to allow broader engagement with Culturally and Linguistically Diverse (CALD) communities, Aboriginal and Torres Strait Islander carers, and LGBTIQ+ carers and persons needing care.

# Recommendations

MHCN recommends that the NSW Government meet the needs of mental health carers through:

- ensuring access to education, supports, and resources including respite
- funding a peer delivered carer service navigation and advocacy support for carers of forensic and corrections patients
- supporting carers to access leisure time through a “NSW Carer Card” as this will lead to an improvement in their wellbeing
- extending the *Disability Advocacy Futures Program* to ensure continued disability advocacy, engagement, and improvement of NSW government services
- ensuring secure housing for persons impacted by psychosocial disability is also needed to improve mental health and wellbeing outcomes.

## 1. Funding for carer education, supports, and resources, including respite services

Mental Health Carers, in association with the Mental Health Coordinating Council (MHCC) has prepared estimates of the cost of these recommended initiatives.<sup>1</sup>

### **Carer Education**

Carer education is vital for carers to feel supported, skilled and knowledgeable about their rights and responsibilities as a carer. MHCN provides limited carer education/skills development events and trainings. However, demand far exceeds the current level of funding. There is a need to increase access to the number of trainings due to the high demand and need. We propose that funding be provided to enable:

- MHCN to provide an additional event each week for a total of 500 additional participants each year, at a cost of \$250 000/year.

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<sup>1</sup> These estimates are also included in the Pre-Budget Submission of the Mental Health Coordinating Council: <https://mhcc.org.au/wp-content/uploads/2024/10/MHCC-Pre-Budget-Proposal-2025-29-Submission.pdf>

- MHCN to provide funding for 5 additional carers per week (250 per year) to access education and skills development delivered by other organisations in NSW at a cost of \$250 000 per year.

### **Support and Resources**

Peer support is held in high regard amongst carers. The Carers NSW National Carer Survey (2024) identified that there is a high level of unmet need in this regard across NSW amongst carers with 36% indicating that they would benefit from online or face to face support (Mylek and Schirmer 2024). Carer Gateway provides key supports to carers in terms of fostering of social connection amongst peers. At the same time, the Carers NSW submission to the Inquiry into the *prevalence, causes and impacts of loneliness in New South Wales* (2024) identified that the needs of certain carers, particularly young carers and male carers were not being addressed under the current mechanisms and models. Supports for LGBTIQ+ carers, CALD carers, and carers of forensic and corrections patients is also needed.

Additional funding should be provided to meet the need for peer supports for mental health carers through carer support groups so that MHCN can:

- Manage funds for 17 additional carer support groups across NSW, one in each Local Health District (LHD) each month, at a cost of \$50,000 per LHD each year.
- Provide additional support services for distressed carers and consumers at a cost of \$1m per year.
- Convene additional carer support groups for specific target groups including older persons, younger persons, LGBTIQ+ carers, Aboriginal and Torres Strait Islander carers, and carers of forensic and corrections patients, at a cost of \$350,000 per year.

MHCN has produced limited information resources specifically for mental health carers which was distributed across NSW on a single initiative. This one-off funding was provided by the NSW Ministry of Health. However, additional resources are now needed to cover other important information for carers, which MHCN could develop and distribute. Additional funding is sought for:

- Development, print, and administration of additional mental health carer information material at a cost of \$150,000 per year.

Mental health carers need information to assist them in their caring role and to ensure the person they care for has access to suitable services. MHCN aims to meet needs in this regard and provides mental health carers with information about their rights and responsibilities,

and relevant services. To ensure that this vital information remains available to mental health carers we recommend that funding is provided for:

- Expanding and improving the MHCN webpage communications, refresh and upgrade of the webpages, and timely maintenance of update to information with additional staff support at a cost of an estimated \$50 000 per year.

Carer Peer workers provide a unique form of support and advocacy to mental health carers based on their own lived experience of caring. However, the number of carer peer workers in NSW is very low. The NSW Ministry of Health provides funding to the Family and Carer Mental Health Program through 5 community-based organisations to provide some access to support services in hospitals and community mental health services across NSW. However, the spread of these services is not universal, and additional support is required for this program to enhance consistency in service delivery across NSW, as hospitals in some parts of the state are not covered directly.

In this regard, MHCN recommends:

- An expansion of the Family and Carer Mental Health Program to employ additional mental health Carer Peer Workers at an estimated cost of \$1m per year, so that all parts of NSW are adequately covered by this important service.

### **Respite**

The 2024 Inquiry into *Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales* recommended that funding for respite must be ensured by the State Government (New South Wales. Parliament. Legislative Council. Portfolio Committee No. 2 - Health. Report no. 64).

MHCN provides a small number of respite grants of \$1000 to mental health carers. This funding is generated by the interest earned by a Trust Fund established from a bequest provided by a supporter, Eunice Lonergan, to MHCN for this purpose. The bequest money can offer up to approximately five respite grants a year. Based on submissions received, there is an unmet need for 800 additional grants each year.

Funding is also needed for Residential Respite services distributed across NSW on a longer-term basis. This funding would enable mental health carers time for study, work, and participation in recreation and other activities. Examples of the current, very limited 'respite type' services are the Recovery Camp run by the Recovery College.

MHCN recommends the NSW Government provide funding for:

- 800 additional grants each year, supported by funding for additional administrative costs of 20%, at a total estimated cost of \$1m per year.
- Expansion of the Residential Respite service to provide one additional respite bed (most likely in a non-government facility) in each LHD, for up to 3 months each year, at an additional cost of \$1m per year.

## 2. Carer Recognition Card

Recognising and valuing the contribution of mental health carers is associated with an increase in their wellbeing. Families, carers and kin make a significant contribution economically and socially in caring for a person experiencing mental ill health and distress. A national study (Diminic et al., 2016) found that it would cost governments \$13.2 billion to replace the caring work of mental health carers with formal mental health support services, indicating that the cost to the State and Federal Governments to address mental health issues would be significantly greater without the contribution of carers.

Carers make difficult financial sacrifices, limiting their access to social and recreational supports. The demands of caring also make it difficult for carers to have enough time for social connections, enjoy leisure time and take a break from their caring role. The recent nationwide Carer Wellbeing Survey (Mylek and Schirmer 2024) reported that just over 50% of carers felt that their caring duties had negative consequences regularly or always on their social life, and 45% indicated that relationships with friends and family had suffered. In NSW, over 60% of carers reported feeling socially isolated (Carers NSW 2024).

The nationwide 2024 Carer Wellbeing survey (Mylek and Schirmer 2024) highlighted that unpaid carers are thrice as likely to report being lonely, and those who often, or always experience loneliness, are nearly five times more susceptible to having low levels of wellbeing compared to carers who were rarely lonely. Addressing these challenges can support the wellbeing of carers. MHCN is of the view that the NSW Government should provide funding for:

- “NSW Carer Card” that would give heavily discounted access to restaurants, sporting events, rebates and other opportunities for entertainment, similar to the Victorian Carer Card, carefully adapted for use in the state of NSW: <https://www.carercard.vic.gov.au/>

A “NSW Carer Card” would be a form of recognition for the contribution that carers make, while also providing carers opportunities for social connection. This would provide options for direct funding to carers to enjoy respite and leisure time, independently from the person they care for. MHCN notes that the NSW Companion Card, which is a much-needed initiative, is distinct from a Carers Card. The Companion Card was set up for persons with significant and permanent disability who cannot participate in activities without a companion, thus the card allows their support person to access activities with them without the additional cost. It is not set up for families and carers of people with mental illness to specifically access leisure time independently without the person they care for.

### **3. Peer delivered carer service navigation and advocacy supports for carers of forensic and corrections patients**

MHCN consults, advocates and co-designs projects with families and carers through convenorship of the *Carers of Forensic and Corrections Patients Network* monthly meetings in collaboration with the Family and Carer Consultant, Justice Health and Forensic Mental Health Network, and the *Mental Health Carer Connection* monthly meetings.

The Family and Carer Consultant provides significant support and advocacy for families and carers to be able to participate in the care and treatment of their loved one. This is particularly significant as the legislation in forensic settings does not oblige treating teams to inform families about key events in relation to the care and treatment of their loved one (see Section 78 of the Mental Health Act 2007). However, there is only person employed in this role across NSW working part-time, and this position does not receive backfill while on leave.

Given the high level of unmet need across the state for supporting families and carers, MHCN recommends that the NSW Government provide funding for:

- 1 FT peer worker being employed in every LHD that would supplement the activities of the Family and Carer Consultant
- 1 FT Family and Carer Consultant.

A peer delivered carer service navigation and advocacy support would work with carers of forensic and corrections patients, as well as with mental health carers of high-risk civil patients in LHD settings.



#### 4. Address Housing and Homelessness (Minister for Housing)

There are major service and co-ordination gaps for when people leave government institutions such as hospital, care, and prison which can result in homelessness. Planning and reviewing existing frameworks such as the *No Exits from Government Services into Homelessness: A Framework for Multi-agency Action*, are crucial to reducing service barriers and support people to enter secure and supported housing. A stable home might prevent re-entry to government institutions, hospital admissions, or homelessness.

People with psychosocial disability and their loved ones are especially vulnerable and require support to maintain housing independence that is responsive to their needs, such as the *Housing and Support Initiative/Community Living Supports*. The NSW Government committed \$20 million to fund the first of three *Haven Hubs* dedicated to NDIS participants with psychosocial disabilities in NSW, starting in the Central Coast.<sup>2</sup> The benefit of 24/7 onsite staff improved relationships between residents and their loved ones as caring roles are better supported. This preventative care-based model reduces risks and mitigates mental distress, demonstrated by decreasing presentations to the emergency department and hospital admissions. Investment and expansion of these programs create net benefits to users, loved ones, hospitals, and government institutions.

Mental Health Carers NSW recommends that the NSW Government:

- Review the *No Exits from Government Services into Homelessness: A framework for multi-agency action* and invest to meet its objectives and the government agency changes needed for its implementation.
- Expand the Housing and Support Initiative and Community Living Supports (HASI/CLS) program to support people with mental illness to live independently in the community with support.
- Expand the Haven Hubs housing programs for NDIS participants with psychosocial disabilities across NSW LHDs to support people with psychosocial disability to receive adequate and dignified care.

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<sup>2</sup> <https://yasmincatley.com/news/media-releases/20-million-for-new-mental-health-housing/>

## 5. Investing in the community sector, advocacy and representation (Minister for Families and Community, Minister for Disability Inclusion)

Representation and advocacy are essential to better government service delivery and reform. As recommended by the *Report on Disability Advocacy Funding*, the NSW The *Disability Advocacy Futures Program* has supported approximately 1.4 million people living with disability in NSW to access NSW Government funded and delivered services since 2022.<sup>3</sup> This program has had success in providing expert advice to government and ministers, and ensuring disability is included across services reviews.

Nevertheless, social and community sectors face significant barriers to delivery including funding contracts and reporting that are too short, inadequately indexed, or do not reflect the actual cost of providing services. Government funders increasingly require engagement with not-for-profits to meet governance and quality and compliance requirements. Accordingly, standard contract durations of less than three years are difficult for not-for-profits to manage as they create barriers to workforce stability and staff retention, longer-term planning, and sustainable delivery and evaluation of service provision. Repeated short-term extensions to existing contracts exacerbate the difficulties as they create administrative, recruitment, and financial problems due to procurement and contract negotiation. Contractors and funders must have adequate time to negotiate contracts and variations outside of the contract duration.

Mental Health Carers NSW recommends that the NSW Government:

- Commit to a minimum five-year extension of the *Disability Advocacy Futures Program* to ensure continued disability advocacy, engagement, and improvement of NSW government services.
- Shift to longer-term funding contracts for services with a minimum of five-years and with longer-durations for programs targeted to disadvantaged and/or hard to reach populations (Aboriginal and Torres Strait Islander peoples, rural/regional).
- All NSW funded contracts must include a buffer period of between six to nine months for funder and contractor to negotiate variations and extensions.

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<sup>3</sup> NSW Government, 2019. *Review into Disability Advocacy in NSW. A Report by the NSW Ageing and Disability Commissioner.*

## References

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