Mental Health Carers NSW

Mental Health Carers NSW Inc.

Members Survey Analysis 2025

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About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience mental health challenges in NSW. MHCN is a community managed organisation that provides systemic advocacy, capacity development and education for the carers, family, friends, and kin of those experiencing mental health challenges across NSW.

In Australia, there are approximately 354,000 mental health carers who, each year, provide 186 million hours of unpaid support.[1] Due to the demands of their caring role, carers are at a high risk of developing mental health issues, as well as experiencing loneliness and social isolation. MHCN supports mental health carers and advocates for services and systems that support them in their caring role. MHCN ensures the voices of mental health carers in NSW, and the people they care for, are represented in policy and service reform processes. We work to uphold the rights of carers and consumers to equitable, accessible, and adequately funded mental health services.

MHCN empowers mental health carers to become champions for mental health reform and advocacy. We engage regularly with carers so they can inform our policy priorities and advocacy; for example, every month we convene the *Carers of Forensic and Corrections Patients Network* meetings, and peer led *Mental Health Carer Connection* meetings.

MHCN also provides the Disability Advocacy Futures Program. This program engages in systemic advocacy on behalf of those who experience psychosocial disability. In this role MHCN advocates to non-Health state government services under the Disability Advocacy Futures Program.

MHCN is funded by the NSW Ministry of Health and the NSW Department of Communities and Justice. We are a foundation member of Mental Health Carers Australia.

[1] Diminic, S., Lee, Y. Y., Hielscher, E., Harris, M. G., Kealton, J., & Whiteford, H. A. (2021). Quantifying the size of the informal care sector for Australian adults with mental illness: Caring hours and replacement cost. *Social Psychiatry and Psychiatric Epidemiology, 56*(3), 387–400.

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Executive Summary

The 2025 Mental Health Carers NSW (MHCN) Member Survey was conducted to inform ongoing quality improvement and ensure that MHCN's advocacy, engagement and member services continue to reflect the priorities of mental health carers across New South Wales.

The survey was in two parts, one focused on the carer's experience of NSW mental health services and the other on the experience of being a member of MHCN and using its services. The survey distributed to 431 members and remained open from 25 June to 19 August 2025. Thirty-two members responded (7.4% response rate). While the response rate was low and findings should be considered indicative rather than representative, the survey provides valuable lived-experience insights into carers' experiences of the mental health system and MHCN's services and are highly consistent with many other investigations.

The findings of the carer experience section demonstrate that despite legislative recognition of carers under the NSW Mental Health Act, many carers continue to experience inconsistent recognition and exclusion from care planning and decision-making. Although General Practitioners and private mental health clinicians were most likely to recognise carers, over half of respondents reported not being recognised or meaningfully included by mental health services. Consent and confidentiality processes were frequently perceived as barriers to collaboration, leaving carers feeling that their expertise and knowledge of the person they support were undervalued.

Carers reported more positive experiences with primary care and community-based services than with acute and hospital settings. However, concerns regarding fragmented care, poor communication, inadequate coordination and limited continuity of care were common across the mental health system. Respondents described repeated information sharing, inconsistent discharge planning and difficulties navigating multiple service systems, highlighting ongoing gaps between policy aspirations for integrated care and carers' lived experience.

The survey also highlights the significant impact of caring on carers' own wellbeing. Burnout, emotional distress, financial pressure, social isolation and declining physical and mental health emerged as dominant themes. Nearly half of respondents reported receiving no formal support, while those accessing support most commonly relied on carer support programs or peer networks. Increased respite, practical assistance, counselling, peer support and system navigation were consistently identified as priority areas for improvement.

Respondents viewed many of the challenges they face as systemic rather than isolated. Workforce capability, service culture, limited psychosocial supports, shortages of community services, and poor coordination between the mental health, disability, justice

and guardianship systems were recurring concerns. Carers consistently described the current system as reactive and crisis-driven, rather than preventative, recovery-oriented and collaborative.

The survey identified clear priorities for MHCN's systemic advocacy. Members called for stronger recognition of carers' rights, improved inclusion in treatment and care planning, greater accountability across mental health services, enhanced workforce education, expanded psychosocial and early intervention supports, and increased investment in respite, housing and recovery-oriented services.

Feedback from the 'MHCN member experience' section regarding MHCN itself was overwhelmingly positive. Satisfaction was high with membership, the Mental Health Carer Connection Meetings, the MHCN website and e-News, reflecting the value members place on MHCN's advocacy, information and engagement activities. At the same time, respondents identified opportunities to strengthen facilitation of member forums, improve accessibility for regional and working carers, increase cultural inclusivity, enhance awareness of available resources, and provide more flexible training opportunities.

Overall, the survey demonstrates that carers continue to face substantial challenges in navigating the mental health system while receiving insufficient recognition and support for their caring role. At the same time, members expressed strong confidence in MHCN's role as an advocate for carers and identified clear priorities to guide future quality improvement.

Since the survey was completed, MHCN has commenced work to address the findings, with the results providing an important evidence base for strengthening member services, informing advocacy priorities, and supporting ongoing mental health system reform that better recognises, includes and supports both carers and the people they care for.

Mental Health Carers NSW

Introduction

The MHCN Member Survey was conducted in 2025, to inform ongoing quality improvement efforts across the organisation. The survey was distributed through Survey Monkey to 431 members in the MHCAN register, and remained open for eight weeks, from 25 June to 19 August 2025.

Participation was voluntary and anonymous, and respondents were not required to answer all questions. A total of 32 responses were received. Response rate was approximately 7.4% which is low, suggesting that findings are indicative, not representative. However, responses still provide valuable lived-experience insights, especially qualitatively.

Survey Findings and analysis

Findings

1. Recognition of Carers and Formal Identification

Critical to supporting carers is their identification by clinicians and service providers, so they can be included in the delivery of care. Survey findings indicate that carers are most commonly recognised by General Practitioners and private psychiatrists or therapists (both 39%), followed by community mental health teams and public hospitals (both 35%). Under the Mental Health Act, carers can be recognised as Designated carers (up to two people nominated by the consumer) or by the treating team (principal care providers, nominated by the treating team). In terms of formal recognition, 45% of respondents identified as a Designated Carer, while 29% reported being recognised as a Principal Care Provider.

The MH Act stipulates that the carer's role must be recognised and supported (s68). However respondents to the survey found that Carers are frequently not recognised or

actively included in care planning, with over half reporting a lack of recognition (57%) and not being offered opportunities to participate (53%).

2. Service Satisfaction Across System Settings

Satisfaction with services is highest for General Practitioners (39%), NDIS-funded support services (38%), and other mental health services (35%). Public hospitals showed notable levels of dissatisfaction, with 26% of respondents reporting negative experiences.

3. Access to Support and Service Utilisation

Nearly half of carers (47%) reported receiving no formal support, with those accessing support most commonly engaging in mental health carer support groups (31%), the Family and Carer Mental Health Program (28%), and other services (28%).

4. Carer Priorities and Key Concerns (Overall Experience)

Carer wellbeing and burnout emerged out to be the strongest theme with 11 of 28 responses (39%) when inquired about the top priority concern. For the second top priority, system navigation and fragmentation with 9 out of 27 responses came out as the strongest priority while workforce and service quality concerns as the third priority concern, with 10 of 27 responses (37%).

5. Priorities Relating to Care of the Person Supported

The top 3 Issues concerning the care of the person supported were Mental health system access, coordination and service quality (9 of 27 responses ~ 33%), service gaps, workforce capability and support availability (8 of 26 responses ~ 31%) and mental health system reform and service model concerns (9 of 26 responses ~ 35%). These issues all relate to creating a cohesive, effective and accessible mental health service system.

6. Advocacy Priorities for MHCN

Respondents most commonly identified improving carer recognition, inclusion, and rights as a priority for MHCN's advocacy (43%), followed by broader system reform, workforce education, and accountability (36%). Carers also highlighted the need for increased

preventative and recovery-oriented supports (29%), including respite, housing, early intervention, and alternatives to crisis-driven care.

7. Priorities for Improving Carer Supports

The most frequently identified priority for enhancing support for carers was increased respite and practical support for carers (36%), including flexible respite options and meaningful breaks from caring responsibilities. This was followed by a need for greater carer recognition, inclusion, and advocacy (32%), particularly in relation to involvement in care processes and information sharing. Respondents also highlighted the importance of expanded peer support, education, and system navigation assistance (29%), including access to carer peer workers, support groups, and guidance through mental health and justice systems.

8. Participation in MHCN Meetings

The most attended meeting according to members was the Mental Health Carer Connection Meeting (MHCCM), with 44% of respondents reporting participating, while 13% had attended both MHCCM and the Carers of Forensic and Corrections Patients Network (CFCPN). Only 6% reported attending CFCPN exclusively, while 38% had not attended either meeting.

9. Satisfaction with MHCN Meetings

Satisfaction with the MHCCM was overwhelmingly positive, with 92% of respondents reporting being satisfied or very satisfied (53% satisfied; 39% very satisfied). No respondents reported dissatisfaction. A minority (20%) reported a neutral response.

Satisfaction with the CFCPN was mixed. A total of 63% of respondents reported being satisfied or very satisfied (38% satisfied; 25% very satisfied), while 33% were neutral and 25% reported being very dissatisfied.

10. Satisfaction with MHCN Membership, Resources and Services

Overall satisfaction with MHCN membership was high, with 82% of respondents reporting being satisfied or very satisfied. Use of MHCN pamphlets was moderate, with 55% of respondents reporting satisfaction. The MHCN website received strong overall satisfaction, with 79% of respondents reporting being satisfied or very satisfied (43% satisfied; 36% very

satisfied). Satisfaction with the e-News was also high, with 76% of respondents reporting satisfaction or very satisfaction. Engagement with MHCN free training was lower than other resources, with 42% reporting satisfaction or very satisfaction among those who completed training (27% very satisfied; 15% satisfied), while 46% had not completed any training.

Discussion

Carer Recognition, Inclusion and Communication

A consistent finding across the survey was that carer recognition remains highly variable across NSW and often dependent on individual practitioners rather than embedded organisational practice. While some carers reported positive experiences, many described needing to actively advocate for recognition and inclusion, despite holding formally recognised caring roles and possessing extensive knowledge of the person they support.

Consent and confidentiality processes were frequently perceived as barriers to meaningful engagement, with carers reporting that services often defaulted to exclusion rather than seeking ways to facilitate appropriate involvement, especially if carers were raising issues about the quality of care. These findings suggest an ongoing tension between consumer autonomy and carer advocacy and inclusion, with many carers feeling that their expertise and long-term knowledge are not adequately valued within care planning and decision-making processes.

Service Quality, Coordination and Continuity of Care

The findings indicate that community-based supports and primary care services are generally viewed more favourably than acute and hospital-based services. However, concerns regarding continuity of care were widespread, particularly during periods of transition between services, hospital admissions and discharges, and interactions across multiple service systems.

Carers frequently described fragmented care pathways, inconsistent communication, and repeated information sharing due to poor record transfer and coordination. These experiences suggest that despite policy emphasis on integrated and person-centred care, carers continue to encounter service systems that operate in silos, creating additional burdens for both carers and the people they support.

Workforce Capability and System Culture

Beyond structural challenges, respondents identified concerns relating to workforce attitudes, capability, and accountability. Many carers perceived that their concerns were dismissed or given insufficient weight, particularly in acute care settings where clinical authority was viewed as overriding lived experience knowledge, regardless of outcomes.

Concerns regarding medication management, responsiveness to risks and side effects, and limited opportunities for collaborative decision-making further contributed to perceptions of exclusion. The findings suggest that improving carer experiences may require not only procedural changes but also cultural shifts that position carers as valued partners in care rather than peripheral participants.

Support Needs and Carer Wellbeing

The survey highlights the significant personal impact associated with the caring role. Carers commonly reported exhaustion, burnout, emotional distress, social isolation, financial strain, and declining physical and mental wellbeing. Many also identified unmet needs for respite, counselling, peer support, advocacy, and practical assistance.

While some supports were valued, carers often described them as limited in duration, difficult to access, or insufficient to meet the complexity of their circumstances. The reliance on self-funded supports reported by some respondents further suggests gaps in the availability of accessible and sustainable carer-focused services.

Mental Health System Challenges

Responses demonstrate that carers view many of their challenges as systemic rather than isolated incidents. Difficulties navigating services, poor communication, lack of continuity, workforce shortages, limited alternatives to emergency departments, and inadequate psychosocial supports were recurring concerns.

Carers also identified shortcomings in the interaction between mental health, disability, justice, and guardianship systems, where fragmented responsibilities can create uncertainty, service gaps, and increased risks. The prominence of these issues across multiple survey questions suggests that carers experience the mental health system as reactive and crisis-driven, rather than coordinated, preventative, and recovery-oriented.

Priorities for Reform

The priorities identified by respondents point towards a desire for both practical improvements and broader system reform. Carers consistently called for stronger recognition and inclusion, greater accountability across services, workforce education, improved coordination, and more recovery-oriented approaches to care. Increased access to respite, psychosocial supports, peer workers, housing, and early intervention

services were also viewed as critical. Responses relating to the NDIS further highlighted concerns regarding access, equity, transparency, and the need for greater recognition of both psychosocial disability and the role of carers. Collectively, these findings suggest that carers are seeking a system that is more collaborative, preventative, and responsive to the needs of both carers and the people they support.

Role of MHCN in supporting carers

Responses indicate that carers value MHCN's advocacy and engagement activities and see an important role for the organisation in advancing carer recognition, system reform, and service improvement. Carers particularly identified the need for increased respite, peer connection, education, navigation support, and advocacy.

While some respondents referred to MHCN support groups, it is important to note that MHCN does not provide formal therapeutic support groups. Rather, MHCN facilitates advocacy and engagement opportunities where informal peer connection may occur. The appearance of these responses may itself reflect broader gaps in the support landscape, with carers seeking support wherever opportunities for connection and understanding are available.

Satisfaction with Online monthly meetings:

Mental Health Carer Connection Meetings

The findings suggest that MHCN's engagement forums are highly valued by those who attend the Mental Health Carer Connection Meetings. The high satisfaction levels indicate that MHCCM is strongly valued as a space for advocacy, peer connection, and having carers' voices heard by decision-makers. However, qualitative feedback suggests that while the meeting is meaningful, there are emerging tensions around facilitation structure and inclusivity. Some participants noted that discussions can become overly detailed or unfocused, indicating a need for more structured, outcome-oriented facilitation. Others highlighted uneven participation, with dominant voices potentially limiting broader engagement.

Accessibility was another key consideration, with carers identifying barriers related to timing (including lack of weekend options), availability for working carers, and limited cultural and experiential diversity within discussions. These findings suggest that while MHCCM is performing strongly in terms of satisfaction and perceived value, its ongoing effectiveness may depend on improving facilitation balance, accessibility, and inclusivity to ensure a wider range of carers can participate meaningfully.

Carers of Forensic and Corrections Patients Network Meetings

The mixed satisfaction levels suggest a more variable participant experience within CFCPN compared to other MHCN forums. While some carers described the group as supportive, kind, and empathetic, others highlighted concerns relating to emotional safety.

There was also a clear need for more structured space for carers to share their experiences regarding both their own wellbeing and the circumstances of the person they support. Overall, the findings suggest that while CFCPN provides valued peer support for participants, improvements in facilitation processes, accessibility, and procedural transparency should be undertaken to ensure consistency of experience and psychological safety for all members.

Satisfaction with MHCN Resources and Training

Overall, findings indicate high satisfaction with MHCN's core resources, particularly membership, website, and e-News, suggesting that MHCN is generally meeting member expectations in terms of information provision and engagement. However, this positive assessment is tempered by consistent themes relating to uneven reach, limited awareness, and geographic inequity, with regional carers frequently reporting that services feel Sydney-focused or insufficiently visible in local systems.

Across resources, a recurring issue is accessibility and usability, including readability of pamphlets, difficulty locating local information on the website, and concerns about the length and relevance of e-News content. These findings suggest that while content quality is generally valued, user experience and tailoring to diverse carer contexts remain areas for improvement.

Engagement with training and additional services was comparatively lower, indicating potential barriers related to awareness, accessibility, and delivery format. Feedback suggests that more flexible, group-based, and recorded training options may improve participation and reduce isolation, particularly for carers balancing intensive caring responsibilities.

Conclusions

MHCN has undertaken work to address the findings of the member survey and to review and improve the survey itself which MHCN now intends to conduct every year. Reviews of the conduct of meetings and the eNews and website have all taken place to improve the member experience. The Carer Experience sections also helped inform and focus MHCN's

systemic advocacy; and henceforth the Carer Experience and MHCN Member Experience sections will be separated to maximise the number of carers who can participate in either. MHCN invites all members and mental health carers to let MHCN how it can improve its support for their needs and will use the results of the 2026 surveys to inform its advocacy in 2026-2027.