National Mental Health and Suicide Prevention Agreement Review

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Acknowledgement of Country

Mental Health Carers Australia (MHCA) acknowledges the Traditional Custodians of the lands on which we work, live and play. We acknowledge that lands were never ceded, and the First Nations peoples experience of historical and ongoing trauma of dispossession and racism. We pay respects to their spiritual ancestors, elders, and emerging leaders across time. We acknowledge with gratitude their sharing of these lands, their strong connection to Country, community and culture, and their strength and the enduring resilience of their living cultures and ways of knowing, being, and doing. We believe we have a precious opportunity to learn about holistic and community-centred approaches to mental and emotional wellbeing from Aboriginal and Torres Strait Islander people.

About Mental Health Carers Australia

MHCA is the nationally funded mental health family, carer and kin peak body, focused solely on the needs of mental health family, carers and kin. We are led by, and represent, the voices of people with lived experience of supporting someone with mental health challenges. MHCA consists of one national and six state and territory organisations. Our aim is to work constructively with governments to improve policies and programs that directly and indirectly impact mental health families, carers and kin.

About mental health families, carers and kin

Mental health family, carers and kin are everyday Australians providing significant emotional, practical and financial support to their family member or friend living with mental health challenges. They do so because there are gaps in available services, requiring them to undertake unpaid work. There are significant, well-documented impacts of this unpaid work, including but not limited to, emotional distress, depression, financial insecurity, employment insecurity and loss of connections with their own family, friends and community.

In 2015, a report by the University of Queensland, commissioned by Mind Australia, estimated that the total annual replacement cost of informal mental health care was $14.3 billion. After adjusting for a $1.1 billion offset from Centrelink payments, the net cost was $13.2 billion.[1] This figure represents what it would have cost governments at the time to replace the support provided by families and informal carers with formal mental health services such as the then-existing Partners in Recovery (PiR) and Personal Helpers and Mentors (PHaMS) programs or disability support workers.

MHCA estimates, that due to inflation and the discontinuation of PHaMS following the introduction of the NDIS, this figure would now exceed $20 billion - likely by a significant margin. For context, the total expenditure on mental health by the Australian and state/territory governments in 2022–23 was estimated at $13.2 billion[2].

Note on language

> *MHCA recognises that individuals who support someone with mental health challenges identify in diverse ways based on their personal experiences and relationships. Some prefer the term "carer", while others identify as a family member, specifying their role (e.g., mother, father, partner, son, daughter etc). Others may identify as a friend, support person, or care partner, emphasising the reciprocal nature of care. To maintain clarity and inclusivity in MHCA submissions, we strive to use concise and broadly inclusive language. For this submission, MHCA will use the term "family, carers and kin."*

Executive Summary

MHCA welcomes the opportunity to contribute to the review of the National Mental Health and Suicide Prevention Agreement (National Agreement). As the national peak body representing the lived experience of mental health families, carers, and kin, MHCA is committed to ensuring an equitable, accessible, and effective mental health and suicide prevention system for all Australians. This submission reflects the perspectives of MHCA member organisations and stakeholders, identifying critical reforms necessary to establish a more effective National Agreement for mental health consumers, their families, carers and kin.

As a national peak body, MHCA does not have the capacity to directly assess the effectiveness of services and programs under the National Agreement. However, a review of the state and territory bilateral agreements has revealed inconsistencies and missing elements. Of particular concern is the complete omission of families in the national and bilateral agreements. Consequently, initiatives and programs addressing their needs have not been implemented.

Given these gaps, MHCA's review focuses on the structure of the National Agreement and provides recommendations on the:

- Opportunities to adopt best practice approaches across Australia, particularly where better outcomes could be achieved.
- Potential unintended consequences, including cost shifting, inefficiencies, or adverse outcomes.
- Effectiveness of the National Agreement's administration, including the integration and implementation of Schedule A, and supporting bilateral schedules.
- Efficacy of reporting and governance arrangements under the National Agreement.
- Applicability of the roles and responsibilities outlined in the National Agreement.
- Complexities of integrating services across jurisdictions and ensuring that the voices of families, carers, and kin are recognised and acted upon.[3]

Key Recommendations

Throughout this submission MHCA makes recommendations in response to each section of the National Agreement. The following key recommendations are considered by MHCA as those which require close consideration by the Productivity Commission, and which will deliver the greatest impact to address the needs of mental health families, carers and kin.

1. Embed principles of relational recovery in both the next National Agreement and accompanying bilateral agreements.
2. Include a clause in the next National Agreement requiring state and territory government funding to fund a mental health family, carer and kin peak body where none exists, or where an existing dedicated mental health family carer organisation lacks peak body status.
3. Conduct an analysis of the unmet needs of families, carers and kin.
4. Review and remodel the Carer Experience Survey (CES) to consider contemporary lived experience developed metrics and engagement mechanisms.
5. Develop specific KPIs for families, carers, and kin and mandate their inclusion in all government services and government-funded organisations. MHCA should be consulted in the development of these KPIs.
6. Fund one metropolitan Mental Health and Wellbeing Connect Centre (including a satellite outreach service), and one rural Mental Health and Wellbeing Connect Centre in each state and territory, excluding Victoria.
7. Establish a Chief Mental Health Family, Carer and Kin Advocate within the Department of Health and Aged Care (DoHAC).
8. Fund MHCA or delegate responsibility to DoHAC to develop a dedicated Mental Health Carer Strategy.
9. Commission a review of the effectiveness of the Carer Gateway in supporting mental health families, carers and kin.

Opening Statement

In 2020, the Productivity Commission's inquiry into mental health highlighted the significant physical, social, emotional, and financial burdens placed on families, carers, and kin when they are left unsupported. Despite this, the National Agreement and its associated bilateral agreements fail to adequately address their needs. There are no actionable commitments, review mechanisms, or targeted programs. This oversight is particularly concerning given the substantial financial and practical contributions families, carers, and kin make to the Australian healthcare system, often at great personal cost to their own well-being.

In 2024 the *Analysis of Unmet Needs Report* found that approximately 230,500 individuals with a 'severe' mental health challenge (aged 12 to 64 years) and a further 263,100 individuals with a 'moderate' mental health challenge were unable to access psychosocial supports. Given that most of these individuals likely receive support from at least one family member or friend, it is reasonable to conclude that a corresponding number of families, carers, and kin also face unmet needs. This is in addition to the unmet needs of families, carers, and kin supporting the 98,818 people accessing the NDIS with a primary or secondary psychosocial disability.[4]

MHCA argues that the scope of the *Analysis of Unmet Needs Report* was too narrow due to the National Agreement's focus on consumer unmet needs. This omission is detrimental, given that unsupported families and carers are nearly twice as likely to experience clinical levels of depression and face a 40% higher risk of poor physical health compared to non-carers.[5] It is vital that the next National Agreement conducts an analysis of the unmet needs of families, carers and kin of people with psychosocial disability and includes the development of strategies and initiatives to address the gap.

Disappointingly, the Carer Gateway remains the primary national mechanism for mental health families, carers and kin to access support, with tailored services outside of the Gateway provided only in Victoria and New South Wales. The House of Representatives *Inquiry into the Recognition of Unpaid Carers* found that generic carer support models fail to account for the unpredictability of mental health crises and their intersections with alcohol and other drugs (AOD), suicide prevention, and the justice system.[6] Without substantial reform, the Carer Gateway will continue to leave many mental health families, carers, and kin unsupported, forcing them to rely on overstretched and inconsistent state-based services.

There remains an incorrect assumption that investments in mental health and suicide prevention programs for consumers will reduce or avoid the need for tailored supports for their families, carers, and kin outside of the Carer Gateway. The next National Agreement should include specific supports for families, carers, and kin in recognition that they are a distinct and critical component of the mental health system. If they fall over, the system falls over.

The next National Agreement presents an opportunity for all jurisdictions to demonstrate their commitment to the National Mental Health Commission's Vision 2030 to achieve whole of system reform. Despite the increasing investment in mental health, distress is increasing, and outcomes are worsening. Governments must work together to address the social determinants of mental health and distress and identify mechanisms to hold governments to account for decisions and actions that result in poor mental health outcomes. It should be led and guided by lived experience experts to ensure that any investment linked to system reform is needed, wanted, and likely to improve outcomes for consumers and their families, carers and kin.

Principles, Objectives, Outcomes and Outputs

Relational Recovery

The National Agreement's guiding principles emphasise person-centred and integrated care, however initiatives to support the consumer to build healthy interpersonal relationships with their families, carers, and kin have not been prioritised. Relational recovery should be based on human rights principles and with a recognition that healthy relationships, families, and communities are the single greatest determinant of mental health and wellbeing.

The next iteration should also explicitly incorporate a relational approach to recovery,[7] emphasising that individuals exist within interconnected networks of family, friends, and community. This approach acknowledges that both the individual, their families and friends require person-centred support, and that strong, mutual relationships based on reciprocity are critical to recovery. Embedding relational recovery as a core principle will provide a framework for meaningful objectives, initiatives and outputs that benefit the whole community.

It must ensure that planned initiatives and strategies do not infringe upon the rights and needs of families, carers and kin. For example, the *National Guidelines to Improve Coordination of Treatment and Support for People with Severe and Complex Mental Illness* defines consumer-led care as: "Coordination of supports is directed by the person with severe and complex mental illness. They have a right to make their own decisions, and these decisions should be respected and supported by carers, communities, services, sectors, and professionals."[8] This is entirely true when those decisions are supported by the family member or friend providing care. However, where there may be disagreement, such as decisions about living arrangements, the family member or carer's rights and interests must also be considered.

> *"If I were to stop helping, the consequences for my daughter would be catastrophic- more hospitalisations, homelessness, or worse. My wellbeing is directly tied to my daughter's survival. This is the reality for many of us, caught in a system that expects everything but offers little in return." (Case Study One)*

There are existing models that are family and relationship-centred that can be scaled up nationally. These are proven alternatives and ways of thinking to the prevailing and failing service models based on individualistic, western notions of self, family, and community:

- The Open Dialogue approach views a consumer's support network as fundamental to recovery. It is based on family therapy principles and is currently being trialled in Victoria and New South Wales.[9]
- The Bouverie Centre in Victoria has made significant advancements using the innovative Single Session Thinking' framework which is internationally recognised and has been successfully implemented in jurisdictional mental health services, Headspace centres, and

Relationships Australia services. The approach offers training for clinicians and practitioners in single session family consultations, single session therapy, and single session thinking for First Nations people.

- First Nations concepts of social and emotional wellbeing is a collectivist approach to an individual's self-concept: the self is inseparable from, and embedded within, family and community. Cultural groups and individuals have their own, unique experiences of social and emotional wellbeing.[10]

These models and concepts are relevant to both mental health and suicide prevention policies and services.

Recommendations

1. Embed relational approaches as a guiding principle in the next National Agreement and accompanying bilateral agreements.
2. Support and expand Open Dialogue trials to all states and territories.
3. Consider the expansion and adoption of Single Session Thinking, including Single Session Therapy and Single Session Family Consultation training, as part of ongoing professional development for clinicians.
4. Provide Carer Lived Experience Peer Workforce training within the 'Single Session Thinking' Framework.

Prevention and Early Intervention

The National Agreement commits to prevention and early intervention, yet these objectives have not been meaningfully extended to support families, carers, and kin. Investing in support for families, carers, and kin is a preventative health measure to:

- Reduce the risk of family members and carers becoming mental health consumers themselves; unsupported carers are nearly twice as likely to experience clinical depression, and 40% more likely to suffer from poor physical health compared to non-carers.[11]
- Prevent adverse outcomes for the person receiving care. Families, carers and kin play a critical role in preventing hospitalisation, homelessness, and suicide and without their support clinical care is likely to fail.[12]

Recommendation 22, of the *Productivity Commission Inquiry into Mental Health* states that governments must commit to more promotion, prevention, and early intervention for families, carers and kin.[13] While some bilateral agreements acknowledge early intervention, MHCA members report that tangible action has been minimal. This represents a missed economic opportunity, as every $1 invested in prevention saves $5-$10 in long-term healthcare costs.[14]

MHCA advocates for increased investment in family, carer, and kin specific prevention and early intervention initiatives, recognising that the estimated $153 million in 2020 by the Productivity

Commission required to meet their unmet needs is relatively modest compared to the potential long-term savings.

Models of support for families, carers, and kin outside of the Carer Gateway that can be expanded and adopted nationally include:

- Mental Health and Wellbeing Connect Centres (Victoria)
- Family and Carer Mental Health Program (NSW)
- Medicare Mental Health Centres (formerly Head to Health Centres) — noting that there are emerging concerns that the model of support for families, carers, and kin is not being consistently implemented.

These programs provide accessible services, including system navigation, referrals, information, and peer support. In particular, the Mental Health and Wellbeing Connect Centres were co-designed by families, carers and kin to ensure the model would be appropriate to their needs.

Recommendations

5. Expand the Victorian Mental Health and Wellbeing Connect Centres to jurisdictions where they do not currently exist, and fund satellite centres in rural and remote areas.
6. Establish and fund a Family and Carer Mental Health Program in all jurisdictions.

Roles and Responsibilities of Each Party

MHCA understands the inter-jurisdictional structures that were established to oversight the implementation of the National Agreement, including the formation of the Mental Health and Suicide Prevention Senior Officials Group and sub-groups. While the structures inform how jurisdictions work together, it is unclear how state and territories incorporate lived experience perspectives – refer Embedding Lived Experience State and Territory below.

The National Agreement fails to assign clear responsibilities for family, carer, and kin supports, leading to systemic gaps and fragmentation. The Productivity Commission 2020 inquiry report recommended that states and territories should be responsible for mental health family, carer, and kin supports:

> *"Carer supports related to the mental health caring role should be planned for and funded by State and Territory Governments… The Australian Government's role would not change. Many mental health families, carers and kin would still interact with the Carer Gateway because it considers their broader support needs, and its services aim to meet goals related to other aspects of their lives (such as health, work, or financial advice)."*[15]

However, mental health family, carer, and kin supports have not been included in state and territory bilateral agreements. This omission may be partly due to the general lack of acknowledgment of families and carers in the National Agreement, and as previously highlighted, the incorrect assumption that the Carer Gateway is a sufficient sole support mechanism

Consequently, this omission has led to systematic neglect of families, carers, and kin within the mental health and suicide prevention sectors. While some states, such as Victoria and New South Wales, have introduced additional supports, others provide little to none, leaving unacceptable numbers of families, carers, and kin without essential services.

Although the National Agreement mandates whole-of-government collaboration, the specific roles and responsibilities remain undefined, leading to funding delays and gaps in service delivery. The lack of regular meetings of health ministers prior to August 2024 to drive reform has further hindered implementation efforts.

While the National Agreement was a good start to building multi-lateral support for reform, it was too narrow in its focus. For example, the action to quantify the unmet needs of people with psychosocial disability could have been broadened to include an analysis of the unmet needs of their families, carers and kin and the identification of system reform options to deliver future non-clinical support services grounded in human rights and inclusion.

Recommendation

7. Include mental health family, carer and kin support initiatives in the next National Agreement, clearly specifying which level of government should be responsible for their design, commissioning and implementation.

Governance Arrangements

Embedding lived experience – State and Territory

The National Agreement underscores the importance of embedding lived experience as a key principle guiding its implementation.

> *Work together to build a better people-centred mental health and suicide prevention system for all Australians, with lived experience of mental ill health and/or suicide of consumers and their families and carers embedded in the design, planning, delivery and evaluation of services (Cl 20a)1 (Clause 20a). (15)*

Only half of state and territories currently fund dedicated mental health family, carer, and kin peak bodies, leading to inconsistencies and gaps in representation nationally. Dedicated peak bodies

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provide essential representation on the specific and unique needs of families, carers, and kin, particularly those interacting with the mental health, emergency services, AOD, suicide prevention and justice systems. Mental health family, carer, and kin peak bodies also represent a broader group of people than those defined as 'carers' under the Carer Recognition Act.

Peak bodies play a vital role in providing expertise and advice to governments on required systemic changes, supporting those who can advocate on their own and providing a voice for those who cannot. They also provide thought leadership, high-level representation, and deep policy advice to governments. Partnering with lived experience peaks across all levels of government early in policy development will produce better outcomes for people.

> *To ensure a truly people-centred mental health and suicide prevention system, the Parties commit to engaging people with lived experience of mental ill health and/or suicide, along with their families and carers, throughout the implementation of this National Agreement (Clause 55).*

A successful example of lived experience inclusion is the partnership between ARAFMI Queensland and the state government. Through proactive engagement, ARAFMI commenced as the peak body for mental health families, carers and kin in Queensland in July 2024.

Peak bodies also enable meaningful lived experience involvement in the co-design, delivery, and evaluation of services within their respective state and territory contexts. For example, Tandem, Victoria's peak body, has demonstrated the effectiveness of collaborative initiatives in delivering co-designed solutions such as the Mental Health and Wellbeing Connect Centres.

Independent family and caregiver peak bodies play a crucial role in ensuring accountability and transparency at the state and territory levels. They also provide Mental Health Carers Australia as the national peak body with direct insight into jurisdictional challenges, concerns, and successes, fostering national accountability.

Recommendation

8. Include a clause in the next National Agreement requiring state and territory government funding of a mental health family, carer and kin peak body where none exists, or where an existing dedicated mental health family carer organisation lacks peak body status.

Embedding lived experience – Nationally

MHCA acknowledges the establishment of the Mental Health and Suicide Prevention Senior Officers Group (MHSPSO), the sub-project working groups, and the formation of a lived experience team within DoHAC, which are positive steps forward in embedding lived experience into system reform.

The next National Agreement should include stronger mechanisms to embed lived experience representation at all levels of decision making. Both levels of government should have robust mechanisms in place to seek the views of consumers, their families, carers, and kin and these should be publicly available. For the purposes of simplicity and transparency for families, carers and kin there should be a multi-lateral agreement, with bilateral agreements being made only to address specific state and territory variations.

Establishing a Chief Mental Health Family and Caregiver Advocate within DoHAC would strengthen recognition of the essential role played by mental health families, carers and kin. This position would raise awareness within government and the broader mental health sector, ensuring that their contributions are acknowledged and incorporated into policy development and decision-making processes. The role would align with the National Agreement's objectives and complement the work of the recently appointed Chief Psychiatrist and Chief Allied Health Officer. It would likewise formalise the inclusion of mental health families, carers and kin in high-level policy development and sector reform initiatives.

Recommendation

9. Establish a Chief Mental Health Family, Carer and Kin Advocate within DoHAC.

Embedding lived experience – PHNs

The absence of a standardised governance framework across PHN's has led to significant variability in service quality, stakeholder engagement, and collaboration opportunities. A primary concern is the inconsistent integration of lived experience perspectives into governance and decision-making processes, now heightened with the discontinuation of the Mental Health Lived Experience Engagement Network. Current arrangements, which depend heavily on executive interest, PHN board autonomy, and contractual obligations with the government, lack robust accountability and transparency mechanisms, and therefore undermine stakeholder trust.

Community Advisory Committees, while a mandated component of PHN governance structures, do not guarantee the meaningful inclusion of lived experience perspectives. This discretionary approach has led to inconsistent implementation and missed opportunities to engage those most affected by mental health service delivery.[16] While a commitment was made in June 2024 to implement the *Lived Experience Governance Framework*, it is now essential to ensure its consistent application across all 31 PHNs.[17]

Lived experience leadership must extend beyond advisory committees to all levels of PHN governance, including boards, executive teams, and commissioning processes. This requires enforceable contractual obligations and the inclusion of measurable Key Performance Indicators (KPIs) to track progress.

Recommendations

10. Mandate lived experience representation at all levels of PHN governance, including boards, executive teams, and advisory committees, with enforceable contractual obligations to ensure compliance.
11. Require PHNs to implement the Lived Experience Governance Framework and include measurable KPIs for lived experience engagement in contractual agreements.
12. Enhance public accountability of PHN performance through annual reporting on lived experience engagement, resource allocation, and service outcomes to promote transparency and stakeholder trust.

Reporting

The National Agreement and the state and territory bilateral agreements lack a systematic approach to monitoring and reporting. Clause 27c stipulates that an annual National Progress Report should serve as a high-level output of the National Agreement, identifying gaps and redundancies in mental health and suicide prevention expenditure. However, significant delays in data collection and reporting hinder timely responses to emerging service gaps. Additionally, recent changes at the National Mental Health Commission have further exacerbated the lack of timely and comprehensive reporting.

Reporting on the National Agreement itself remains inadequate. The most recent annual report covers the 2022–2023 financial year but lacks substantive evidence beyond indicating the number of initiatives assigned a completion rating.[18] There is little detail regarding which initiatives have progressed, stalled, or experienced inaction. This highlights the poor quality of reporting and the lack of accountability.

Moreover, families, carers, and kin, who were omitted from the National Agreement and bilateral agreements, receive minimal or no reporting on how the National Agreement impacts them. More inclusive monitoring can be achieved by leveraging existing frameworks such as the *National Mental Health Service Planning Framework* (NMHSPF)), which provides a structured approach to planning and resourcing mental health services based on population needs. Incorporating measures that assess the social, emotional, and financial well-being of mental health families, carers, and kin would ensure their experiences are adequately captured.

Recommendations

13. Establish a clear mechanism to ensure the annual National Progress Report is released on schedule using a revised, fit-for-purpose template that enhances transparency and accountability regarding initiative progress.
14. Develop inclusive monitoring mechanisms for families, carers, and kin through improved and dedicated data collection.

Data and Evaluation

Data

A significant barrier to adequately supporting families, carers, and kin is the lack of comprehensive data collection. National datasets, such as the *Primary Mental Health Care Minimum Data* Set (PMHC MDS) and *the National Outcomes and Casemix Collection (NOCC),* focus primarily on consumer outcomes, with mental health family and caregiver-specific measures either limited or absent. The *Health of the Nation Outcomes Scales for Children and Adolescents* (HoNOSCA) contains only basic satisfaction metrics, further restricting visibility into the distinct experiences and needs of mental health families, carers, and kin.

A particularly concerning gap is the lack of data on families, carers, and kin supporting individuals experiencing suicidality. Their role in providing care must be recognised independently of mainstream mental health services. Comprehensive data collection is vital to ensure families, carers, and kin are not viewed merely as an extension of the workforce, but as individuals requiring dedicated consideration and support. The National Suicide Prevention Office's national suicide and self-harm monitoring system was established to improve data quality and accessibility in suicide prevention, underscoring the importance of robust data in shaping effective interventions.[19]

> *"I have PTSD as a result of my own child abuse; however, I had reached a point where it was manageable and almost non-existent in my daily life. Since my daughter's severe mental health deterioration, I have been re-traumatised and now experience PTSD symptoms again. In the past six months, I have been diagnosed with Functional Neurological Disorder (FND), which my specialists attribute to severe and constant stress. Due to the overwhelming stress, carer burnout, deteriorating health, lack of support, and utter hopelessness, I attempted to take my own life." (Case Study Two)*

Currently, there is no mechanism to identify and address the mental health needs of families, carers and kin, preventing the implementation of effective prevention and support measures. This data is essential, as research has found that 71% of mental health families, carers, and kin experience suicidal thoughts, 1 in 6 are likely to attempt suicide, and 1 in 10 have already attempted.[20]

Data accuracy is another significant issue, particularly regarding unrecorded rates of suicidality and the lived experiences of Aboriginal and Torres Strait Islander communities. Existing datasets often fail to represent the realities of families, carers, and kin, limiting policymakers' ability to develop evidence-based interventions.

Furthermore, anecdotal evidence suggests that the *Carer Experience Survey (CES)* is not fit-for-purpose and is inconsistently implemented across jurisdictions. Unlike the *Your Experience of Service (YES*) survey, which is publicly available via the Australian Institute of Health and Welfare (AIHW), the CES lacks uniform adoption and transparent reporting. While the National Agreement commits to improving data collection and transparency, the inconsistent use of the CES limits insight into the experiences of families, carers and kin. Without appropriate and timely data, the National Agreement will fail to deliver meaningful outcomes for them.

The improvement of data collection and inclusion of family, carer, and kin metrics should coincide with a supported and empowered National Mental Health Commission (NMHC) to strengthen and fulfil its role in producing a comprehensive Report Card. The challenges of federalism and obtaining data from jurisdictions, together with the cross-portfolio scope of focus beyond health, mean the functions of the NMHC require considerable strengthening, including own-motion powers to obtain relevant data from jurisdictions across portfolios. The NMHC should also be able to provide advice to states and territories policy where appropriate. This should coincide with a focus on family, carer, and kin outcomes through a rights-based (social, economic and cultural) lens.

In our submission to the "*Reforms to Strengthen the National Health Commission and National Suicide Prevention Office"* discussion paper, MHCA expressed support for the proposed functions of monitoring, reporting and advising for the NMHC. However, it must be independent to perform its duty to hold governments and sectors accountable. Without this independence, the biomedical culture that underpins Australia's resistance to reforming legislation to align with human rights obligations will continue to create a conflict of interest,

Recommendation

15. Review and remodel the Carer Experience Survey (CES) to consider contemporary lived experience developed metrics and engagement mechanisms
16. Develop specific KPIs for families, carers, and kin and mandate their inclusion in all government services and government-funded organisations. MHCA should be consulted in the development of these KPIs.
17. Conduct an analysis of the unmet needs of mental health families, carers and kin.
18. Require that the National Suicide and Self-Harm Monitoring System assess data on the experiences of families, carers, and kin supporting individuals with suicidality, as well as their own risk of suicidality.
19. Establish the NMHC as an independent, primary statutory body outside of DoHAC, undertaking a robust co-design process to ensure its independence.

Evaluation

The recently released *National Mental Health and Suicide Prevention Evaluation Framework (NMHSPEF)* acknowledges the role of mental health families, carers, and kin but fails to provide distinct mechanisms for measuring their involvement in care and evaluation processes. The framework tends to conflate carers with consumers, reducing accountability in service delivery and reform. Without specific evaluation measures, there is no assurance that the contributions and challenges faced by families, carers, and kin are being adequately considered.

The NMHSPEF emphasises the need for comprehensive data collection, enhanced feedback mechanisms, and evidence-based service delivery to improve inclusion. However, for the framework to be truly effective, it must explicitly incorporate dedicated metrics for mental health families, carers and kin.

Additionally, the *2020 Productivity Commission Review* recommended that the Department of Social Services (DSS) evaluate the outcomes achieved for mental health families, carers and kin through its Carer Support Program.[21] However, there has been no public reporting confirming whether this evaluation has taken place, raising concerns about the follow-through on these recommendations.

Furthermore, existing cultural evaluation frameworks for First Nations data could be adapted to better assess the needs of other priority groups, such as Culturally and Linguistically Diverse (CALD) communities and LGBTQIA+ individuals, as well as families, carers and kin.

Recommendations

20. Review the NMHSPEF to include dedicated metrics for families, carers and kin.
21. Conduct an evaluation—with publicly available reporting—on the outcomes achieved for families, carers and kin through the Carer Support Program.
22. Explore the adaptation of cultural evaluation frameworks used for First Nations data to assess the needs of other priority groups (e.g., CALD, LGBTQIA+) and families, carers and kin.

National Priorities

Priority Populations – Families, carers and kin

The National Agreement fails to explicitly recognise families, carers and kin as a priority population. The MHCA views this as a significant oversight, as evidence indicates that families, carers and kin experience higher levels of psychological distress than the general population.[22]

Current support mechanisms, such as the Carer Gateway, do not adequately address the needs of mental health families, carers, and kin, who face distinct and complex challenges compared to other carers. Additionally, the *National Carer Strategy* lacks dedicated consideration for mental health families, carers, and kin, highlighting the urgent need for a mental health-specific strategy. The strategy should also consider the needs of those who are not the primary support person but who are also impacted, including siblings.

Findings from the *2024 Carer Wellbeing Survey*[23] further emphasise the disadvantage experienced by mental health and alcohol and other drug (AOD) families, carers, and kin. Compared to the average carer, they reported:

- Lower overall wellbeing
- Higher levels of psychological distress
- Poorer general health

- Increased loneliness
- Reduced financial wellbeing.

These disadvantages are particularly pronounced among individuals who provide 40 or more hours of care per week and those who care for multiple people, which account for 40% and 25% of mental health families, carers and kin, respectively.[24]

Beyond these challenges, mental health families, carers, and kin frequently experience violations of their fundamental rights, including safety, choice, self-determination, participation in employment and education, and access to public services. Academic research has questioned the adequacy of current recognition frameworks, highlighting that they fail to protect a socially and economically disadvantaged group.

For example, a University of Queensland (UQ) report found that approximately 40% of primary mental health families, carers and kin provide 40 or more hours of care per week - equivalent to a full-time job, yet without the rights, leave entitlements, or protections provided under the Fair Work Act.[25] This constitutes exploitative labour, leaving families, carers, and kin mentally, physically, and financially vulnerable while simultaneously filling critical gaps in the mental health system.

The omission of families, carers, and kin from the National Agreement has contributed to significant human rights infringements. Many are left solely responsible for supporting their loved ones, with little to no support. Anecdotal evidence suggests that individuals in crisis are often discharged into the care of their family member without their knowledge or consent, sometimes within hours of a mental health crisis or suicide attempt. These family members receive no follow-up support and are expected to provide care despite their own emotional and psychological trauma.

> *"After this incident, I called the emergency department and asked them not to discharge her until the morning. I needed time to decompress and process what I had just gone through. Despite my request, an hour later, my daughter was discharged and turned up at home... When she walked in, she verbally abused me for calling 000 and for having a neighbour over and eating something. In her eyes, it looked like I didn't care." – (Case Study Three)*

While the *Carer Recognition Act 2010* (Cth) exists, it lacks legal authority to enforce compliance or require government services to uphold its principles. The next National Agreement presents an opportunity to ensure that state and territory governments practically implement key objectives of the legislation.

A scalable, evidence-based solution is the establishment of Mental Health and Wellbeing Connect Centres in all states and territories (excluding Victoria, where the model was co-designed and currently exists). These centres leverage existing rural and remote services as outreach mechanisms and provide:

- Individual peer support

- Family therapy
- Education
- Information, resources, and referral assistance
- Advocacy

In addition, state and territory governments should fund Family and Carer Mental Health Programs, which offer:

- Psychoeducation
- Training programs
- Information and resources
- One-on-one support
- Peer support
- Advocacy
- Clinical services
- Health promotion activities

Priority Populations – People experience or at risk of abuse and violence

The MHCA highlights the urgent need to address the abuse and violence experienced by mental health families, carers and kin. Currently, family violence services in Australia do not adequately respond to the unique and complex nature of violence directed at family members. Most existing domestic and family violence services are designed for women escaping intimate partner violence; and children experiencing abuse from parents or guardians.

However, they are often unable to appropriately support mental health families, carers, and kin. For example, a Carer Peer Worker in Queensland reported referring a family member to a local domestic and family violence service after experiencing violence from the person they cared for. The service refused assistance, stating they were not equipped to handle this type of case.

MHCA acknowledges that mental health challenges do not inherently make an individual dangerous or violent. However, when violence does occur, research shows it is more likely to be directed at family members. [26]A systematic review found significant international research on violence against family members by individuals living with severe mental health challenges.[27] Studies indicate that family members frequently experience physical, verbal, psychological, and financial abuse. The next National Agreement should include initiatives to better understand and respond to family violence.

Recommendations

23. Fund one metropolitan Mental Health and Wellbeing Connect Centre (including a satellite outreach service), and one rural Mental Health and Wellbeing Connect Centre in each state and territory, excluding Victoria.
24. Fund MHCA to provide national coordination and leadership in establishing Mental Health and Wellbeing Connect Centres.
25. Fund MHCA or delegate responsibility to DoHAC to develop a dedicated Mental Health Carer Strategy.
26. Commission an independent review to assess the effectiveness of the Carer Gateway in supporting mental health families, carers, and kin.

Priority Populations – Rural and remote

MHCA and its members recognise the ongoing challenges faced by Australians living in rural and remote areas, who remain significantly underserved in mental health care. The sector continues to be dominated by the prevailing medical model, as reflected in mental health service expenditure. Government mental health services and public hospitals receive most of the funding, while non-government organisations (NGOs) receive significantly less recurrent funding than other services.[28]

Access to mental health services in rural and remote areas remains limited due to several factors, primarily the dispersed and smaller populations that make service provision less cost-effective. Additionally, sourcing and retaining a skilled workforce remains an ongoing challenge.

The National Agreement and bilateral agreements have not effectively addressed the numerous barriers faced by individuals living in rural and remote regions. Digital accessibility remains a significant issue, with disparities in access, affordability, and digital literacy, often referred to as the "digital gap", being particularly pronounced for First Nations people and those living outside urban centres. [29] This is a critical oversight, given that many of the services and initiatives outlined in the National Agreement and bilateral agreements rely on digital platforms for delivery.

Consultations conducted by ARAFMI Queensland highlight further concerns, revealing that families, carers, and kin, and service users in rural areas frequently face long travel distances and limited access to coordinated care. While the Medicare Mental Health Centres (formerly known as Head to Health Centres) have demonstrated some success, substantial service gaps persist, exacerbated by ongoing shifts in responsibility between state and national governments. In contrast, the Mental Health and Wellbeing Connect Centres have proven effective in supporting rural and remote families, carers, and kin.

Recommendations

27. Ensure equitable access to innovation funding from PHNs and state and territory governments, prioritising programs that address service gaps in rural and remote areas while fostering peer-led, community-based mental health initiatives.

Stigma and Suicide Prevention and Response

The establishment of the National Suicide Prevention Office (Clause 27h) and the National Suicide Prevention Strategy (NSPS) is a positive step forward. The NSPS is a well-developed strategy, and MHCA looks forward to informing its implementation, particularly in how it might support families, carers, and kin affected by suicide. MHCA proposes that the Mental Health and Wellbeing Connect Centres are fit for purpose to deliver several actions, including peer support for families, carers and kin.

Clause 114 of the National Agreement mandates the development of a National Stigma and Discrimination Reduction Strategy. While the consultation for this strategy concluded in February 2023, the final strategy has yet to be released. Past stigma reduction campaigns have not sufficiently addressed the stigma and discrimination faced by mental health families, carers, and kin, particularly from clinicians, service providers, and the wider community.

> *Government child and adolescent mental health services have failed and traumatised me and my daughter. Despite my daughter telling psychiatrists that she is not ready to explore her trauma, they press anyway. We even had a psychiatrist spend the session talking about philosophy rather than providing therapeutic care. I have been systematically excluded from my daughter's care. Reports have gone from describing me as an "over-bearing" parent, to saying I am "not taking this seriously". I have been trying to tell services what is happening, what she and I are going through at home. (Case Study Two)*

Recommendations

28. The immediate release of the National Stigma and Discrimination Reduction Strategy.
29. The development of a targeted stigma and discrimination reduction campaign for mental health families, carers and kin. This should be included within a broader Mental Health Carer Strategy, with MHCA leading this initiative.

Psychosocial Supports outside of the NDIS

Significant service gaps for people with psychosocial disability persist due to the lack of political will. The 2025-26 Federal Budget has not included enhanced funding for psychosocial supports outside of the NDIS despite the well documented evidence including the Productivity Commission's Inquiry into Mental Health supporting this as a priority.

The system remains under-funded, fragmented and lacks a clear vision. While individual agencies have responsibility for various reforms relating to psychosocial disability there lacks an overarching plan with associated accountabilities. As an example, the Department of Social Services is responsible for designing targeted foundational supports, the Department of Health and Aged Care, states and territories are responsible for designing psychosocial supports outside of the NDIS, and the NDIA is responsible for psychosocial reforms within the NDIS. No single minister has overall oversight and accountability for psychosocial reforms. The lack of accountability and stalling of reform work results in families, carers and kin continuing to fill the service gaps.

Similarly, there is no single agency responsible for commissioning psychosocial supports with the NDIA, PHNs and states and territories currently commissioning services. PHNs which were established to commission gaps in services for primary health were asked to commission the Commonwealth Psychosocial Support Program, which delivers a social model of support. As a result, their ability to deliver programs grounded in a social model of care is limited by their historical focus on primary health and clinical services.[30] This structural limitation makes the PHN model unsuitable for commissioning services for the 230,000 Australians who, due to broader systemic gaps, lack access to psychosocial supports.[31]

While the Productivity Commission recommended transitioning psychosocial commissioning responsibilities to state and territory governments it was not included in the National Agreement, with a continued reliance on PHNs to commission psychosocial supports. Further sector consultation should be undertaken to determine the most appropriate commissioning mechanism to ensure equity of access to service and consistency in delivery of the service model.

MHCA advocates for a best-practice, lived experience-led commissioning model to ensure psychosocial supports are recovery-oriented, community-informed, and integrated with clinical mental health care.[32]

Ideally all psychosocial reforms should be led by one agency and all psychosocial supports commissioned by one commissioning body to facilitate an integrated system and ‘customer-centric’ approach. Furthermore, long-term funding arrangements should prioritise an independent commissioning process free from conflicts of interest, guided by lived experience leadership, and supported by robust accountability mechanisms.

Recommendations

30. The Australian Government should consult stakeholders, including jurisdictional and lived experience representatives, to determine the most effective and equitable structure for psychosocial commissioning.
31. Integrate PHN commissioning activities for the Commonwealth Psychosocial Support Program in the short term through joint planning processes with states and territories to enhance coherence and reduce duplication.
32. Mandate Lived experience involvement in the design, implementation, and evaluation of commissioned services, particularly where lived experience-led commissioning models are not yet established.
33. Establish a new, independent, lived experience-governed commissioning body to oversee block funding for community-managed organisations.

Regional Planning and Commissioning

The National Agreement has not achieved its goal of integrated and collaborative regional planning and commissioning. Despite guidelines requiring PHNs and Local Health Networks (LHNs) to engage in joint planning, many of the intended objectives remain unfulfilled. Key gaps include partnerships between PHNs and state/territory health systems, collaborative data-sharing agreements, and alignment with broader mental health strategies.

A critical challenge is balancing regional flexibility with national consistency. While PHNs' regional focus allows them to tailor services to local needs, this flexibility has resulted in significant variability and fragmentation across the 31 PHNs. Members have expressed concerns that access to mental health programs is often determined by geographic boundaries, creating inequities for those seeking support. This fragmented approach has made it increasingly difficult for consumers, families, carers, and kin to navigate the system, undermining equitable access to care.

Furthermore, while some PHNs and LHNs have aligned boundaries, many do not. Misaligned boundaries lead to inefficiencies, duplication, and fragmented care. Aligning PHN boundaries with LHNs or equivalent state-based health districts, as recommended in the 2014 Horvath Review of Medicare Locals,[33] would improve service integration and consistency. However, any realignment must also account for regional differences to ensure PHNs can continue addressing local needs effectively.

Strengthening joint planning between PHNs and state systems is essential. Establishing comprehensive data-sharing agreements between PHNs and jurisdictional health systems would facilitate better resource allocation, addressing service gaps and improving care coordination. Collaborative frameworks supported by robust data-sharing mechanisms would enhance service alignment and integration.

> *It seems to me that what is missing is connection between services. It all seems a bit transactional with each service focussing on one part of the person. I'm left trying to connect things together for my son and he gets quite confused about why this service doesn't 'talk' to another service (Case Study 4)*

Currently, the existing framework that informs service commissioning is the NMHSPF, released in 2019. The framework uses stigmatising language, preferencing clinical and outdated models over rights-based community supports. The NMHSPF in its current state does not articulate the range of supports that should be commissioned to deliver on the NMHC's Vision 2030, which 'conceptualises a unified system that takes a whole-of-community, whole-of-life and person-centred approach to mental health; a vision to provide easily navigated, coordinated and balanced community-based services that are offered early to meet each individual's needs and prevent escalating concerns'.[34]

A successful example of a contemporary approach to service planning is the co-funded Urgent Mental Health Care Centre in South Australia. Supported by the PHN via the Medicare Mental Health Centre initiative and SA Health, this 24/7 facility provides immediate, person-centred care.[35] Designed with input from both lived experience and clinical expertise, it demonstrates how effective partnerships can deliver accessible and responsive mental health services.

The National Agreement mandates the development of national guidelines for regional commissioning, and commits to the NMHSPF taxonomy, which includes supports for carers. However, a review of bilateral agreements indicates that carer supports are rarely planned and commissioned in accordance with this taxonomy, and existing services are inconsistently provided across jurisdictions.

Recommendations

34. Consider the realignment of PHN boundaries with LHNs or equivalent state-based health districts to improve service coordination, reduce inefficiencies, and ensure equitable access in the next National Agreement.
35. Establish collaborative data-sharing agreements across PHNs, states and territories to ensure comprehensive and meaningful data is available for regional planning and service integration.
36. Strengthen co-design efforts by mandating engagement with lived experience consumers and carers in all PHN planning, commissioning, and evaluation processes.
37. Review the NMHSPF to reflect and inform contemporary, non-clinical approaches to service commissioning.

Workforce

The National Agreement and state and territory bilateral agreements emphasise workforce development, particularly within the clinical and practitioner workforce. However, MHCA is concerned about the lack of focus on strengthening the Lived Experience Peer Workforce.

There remains a concerning lack of carer peer workers across government, government-funded, and PHN-funded mental health and suicide prevention services. Consultations with our members also indicate a significant disparity between the number of carer peer workers and consumer peer workers.

While some states and territories have independently introduced support and training initiatives for carer peer workers, these efforts remain inconsistent across Australia. Since its inception, organisational readiness for the lived experience workforce has been a persistent challenge. Some progress has been made through state-led initiatives, such as Tandem's Carer Lived Experience Workforce (CLEW) network. Carer peer workers play a critical role in delivering a relational approach to mental health care and are essential to improving the wellbeing of families, carers, and kin.

Additionally, access to formal mental health peer work qualifications varies across states and territories. To address this, all states and territories must ensure that Technical and Further Education (TAFE) institutions offer the Certificate IV in Mental Health Peer Work and integrate appropriate workplace experience into the qualification. This aligns with Action 1.3.1 of the National Mental Health Workforce Strategy, which calls for strengthening workforce pathways through education.[36]

The next National Agreement should include an initiative to improve workforce competencies in relational and family-centred practice. The initiative should be lived experience designed and led and relational knowledge incorporated into educational settings and mandated in commissioning activities.

Recommendations

38. Include a requirement that all government mental health services, government-funded, and PHN-funded mental health services receive training in relational and family-centred practice.
39. Require all government mental health services, government-funded, and PHN-funded mental health services to maintain an equal allocation of consumer and family/carer full-time equivalent (FTE) roles.

Conclusion

Despite the Productivity Commission's comprehensive analysis in 2020 of the significant impacts of caregiving on families, carers, and kin, the current National Agreement and state and territory bilateral agreements have failed to adequately recognise or respond to their needs.

This submission underscores that families, carers and kin experience disproportionately high levels of psychological distress, poorer physical health, and financial insecurity compared to non-carers. The reliance on generic carer support models like the Carer Gateway, has proven insufficient in addressing the unique and complex challenges faced by those supporting individuals with mental health challenges, particularly during crises.

MHCA strongly advocates for fundamental changes in the next iteration of the National Agreement. Key recommendations include embedding a relational recovery approach, establishing dedicated family, carer, and kin support programs, ensuring the inclusion of lived experience at all levels of governance, improving data collection and reporting, and recognising families, carers and kin as a distinct priority population with needs mapped against specific KPIs. The case studies vividly illustrate the immense burdens and lack of support experienced by mental health families, carers, and kin, highlighting the urgent need for systemic change.

Without significant and intentional reforms, this crucial segment of the population will continue to be overlooked, with detrimental consequences for their own wellbeing and the wellbeing of the individuals they support, ultimately undermining the goals of an equitable and effective mental health system.

Table of Recommendations

All Recommendations

Relational Recovery

1. Embed relational approaches as a guiding principle in the next National Agreement and accompanying bilateral agreements.
2. Support and expand Open Dialogue trials to all states and territories.
3. Consider the expansion and adoption of Single Session Thinking, including Single Session Therapy and Single Session Family Consultation training, as part of ongoing professional development for clinicians.
4. Provide Carer Lived Experience Peer Workforce training within the 'Single Session Thinking' Framework.

Prevention and Early Intervention

5. Expand Medicare Mental Health Centres to jurisdictions where they do not currently exist, and fund satellite centres in rural and remote areas.
6. Establish and fund a Family and Carer Mental Health Program in all jurisdictions.

Roles and Responsibilities of each party

7. Include mental health family, carer and kin support initiatives in the next National Agreement, clearly specifying which level of government should be responsible for their design, commissioning and implementation.

Governance Arrangements

Embedding Lived Experience – State and Territory

8. Include a clause in the next National Agreement requiring state and territory government funding of a mental health family, carer and kin peak body where none exists, or where an existing dedicated mental health family carer organisation lacks peak body status.

Embedding Lived Experience – Nationally

9. Establish a Chief Mental Health Family, Carer and Kin Advocate within DoHAC.

Embedding Lived Experience – PHNs

All Recommendations

10. Mandate lived experience representation at all levels of PHN governance, including boards, executive teams, and advisory committees, with enforceable contractual obligations to ensure compliance.
11. Require PHNs to implement the Lived Experience Governance Framework and include measurable KPIs for lived experience engagement in contractual agreements.
12. Enhance public accountability of PHN performance through annual reporting on lived experience engagement, resource allocation, and service outcomes to promote transparency and stakeholder trust.

Reporting

13. Establish a clear mechanism to ensure the annual National Progress Report is released on schedule using a revised, fit-for-purpose template that enhances transparency and accountability regarding initiative progress.
14. Develop inclusive monitoring mechanisms for families, carers, and kin through improved and dedicated data collection.

Data and Evaluation

Data

15. Review and remodel the Carer Experience Survey (CES) to consider contemporary lived experience developed metrics and engagement mechanisms
16. Develop specific KPIs for families, carers, and kin and mandate their inclusion in all government services and government-funded organisations. MHCA should be consulted in the development of these KPIs.
17. Conduct an analysis of the unmet needs of mental health families, carers and kin.
18. Require that the National Suicide and Self-Harm Monitoring System assess data on the experiences of families, carers, and kin supporting individuals with suicidality, as well as their own risk of suicidality.
19. Establish the NMHC as an independent, primary statutory body outside of DoHAC, undertaking a robust co-design process to ensure its independence.

Evaluation

20. Review the NMHSPEF to include dedicated metrics for families, carers and kin.
21. Conduct an evaluation—with publicly available reporting—on the outcomes achieved for families, carers and kin through the Carer Support Program.

All Recommendations

22. Explore the adaptation of cultural evaluation frameworks used for First Nations data to assess the needs of other priority groups (e.g., CALD, LGBTQIA+) and families, carers and kin.

Priority Populations

23. Fund one metropolitan Mental Health and Wellbeing Connect Centre (including a satellite outreach service), and one rural Mental Health and Wellbeing Connect Centre in each state and territory, excluding Victoria.
24. Fund MHCA to provide national coordination and leadership in establishing Mental Health and Wellbeing Connect Centres.
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Stigma and Suicide Prevention Response

28. The immediate release of the National Stigma and Discrimination Reduction Strategy.
29. The development of a targeted stigma and discrimination reduction campaign for mental health families, carers and kin. This should be included within a broader Mental Health Carer Strategy, with MHCA leading this initiative.

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30. The Australian Government should consult stakeholders, including jurisdictional and lived experience representatives, to determine the most effective and equitable structure for psychosocial commissioning.
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33. Establish a new, independent, lived experience-governed commissioning body to oversee block funding for community-managed organisations.

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Regional Planning and Commissioning

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37. Review the NMHSPF to reflect and inform contemporary, non-clinical approaches to service commissioning.

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38. Include a requirement that all government mental health services, government-funded, and PHN-funded mental health services receive training in relational and family-centred practice.
39. Require all government mental health services, government-funded, and PHN-funded mental health services to maintain an equal allocation of consumer and family/carer full-time equivalent (FTE) roles.

Attachment A - Case Study One

I am a mother of an adult daughter living with serious mental illness. Our journey has been complicated by distance, as I live interstate, a decision I made after she seemed to find stability as a younger married woman and new mum. But everything changed dramatically. Her marriage broke down under the weight of coercive control, emotional distress, and eventually, a relapse into severe bipolar disorder presentation. This was one of many relapses compounded by financial instability as she struggled to survive on a Disability Support Pension (DSP). The complexity of supporting her from afar, while carrying the emotional burden of watching her world unravel, is a pain that words barely capture.

One of the hardest realities to face has been my daughter's loss of access to her own child due to the severity of her illness. The pain of witnessing her struggle with suicidal ideation and attempts, knowing she feels the void of separation from her daughter every day, is indescribable. There is a constant ache in my heart, a fear that never leaves – that one day, her pain may become too overwhelming.

The emotional toll of supporting her from a distance is immense. The phone calls at all hours, the panic at every missed call, the helplessness of not being able to give her a hug or offer comfort in person. This isn't just emotional exhaustion; it's heartbreak, repeatedly.

Being a long-distance carer is isolating. I am constantly torn between the need to be present for her and the reality of my own life interstate. This situation has affected my marriage, friendships, my ability to socialise, and even my professional life.

People often don't understand why I can't just 'move back,' or why I seem distracted, anxious, or withdrawn. There are days when I feel utterly alone – like no one truly understands the complexity of my situation.

Social isolation is real. It's the missed family events, the friends who stopped calling because they don't know what to say, and the constant juggle between duty and distance.

Financially, this journey has been devastating. My daughter lives in extreme poverty, surviving on a DSP that barely covers her basic needs. The financial burden on us is enormous – we must supplement her income to cover essential costs that fall outside the DSP. This includes funding private health insurance that we haven't even been able to use, because the acuity of her condition isn't suitable for private sector care.

I often find myself choosing between my own needs and hers, juggling bills and debts, knowing that if I don't help, she may not survive. The pressure is relentless. It's not just the monetary cost; it's guilt, the worry, the feeling of never being able to do enough.

This situation has taken a toll on my own health and wellbeing. The constant worry, the sleepless nights, and the ongoing emotional strain have left me exhausted. But I don't have the luxury of breaking down – if I fall apart, who will be there for her? I am painfully aware that our healthcare system relies on carers like me to hold things together without offering the support we desperately need.

If I were to stop helping, the consequences for my daughter would be catastrophic – more hospitalisation, homelessness, or worse. I am just one person, but my wellbeing is directly tied to my daughter's survival. This is the reality for many of us, caught in a system that expects everything but offers little in return.

I share my story because behind every statistic is a family struggling to stay afloat. I share it to bring a face to the numbers, to humanise the policies and systems that too often overlook the people they are meant to serve.

I want my colleagues and others to see beyond the data – to understand that this is not just about costs or services, but about lives, about love, about survival. I hope that by sharing my lived experience, we can begin to have honest conversations about what carers truly need – financial support, emotional respite, and systemic change. My story is just one, but it echoes the voices of countless others who live in the shadows, doing their best in impossible circumstances.

We need change, and it begins with understanding the real impact of serious mental illness on families like mine.

Attachment B - Case Study Two

For the last 4 years since my daughter was 10, I have been supporting her and her significant and complex mental health challenges. After several highly traumatic experiences, my daughter now has PTSD, co-occurring with autism. Except, I know there is something more. She has gotten progressively more unwell, and it seems that, as she has gotten more unwell, the supports that should be there are all missing. My daughter has attempted suicide more times than I can count, experiences self-harm, hallucinations, and changes in personalities. We have a NDIS plan, but the behavioural support workers are simply not qualified enough to support my daughter and her complex needs. I have had to advocate for my daughter to, not only receive any form of support, but also appropriate and specialised support. Outside of government services there are no supports for me or my daughter. Except, the government services we need to access are an hour's drive away from where I live.

Government child and adolescent mental health services have failed and traumatised me and my daughter. Despite my daughter telling psychiatrists that she is not ready to explore her trauma, they press anyway. We even had a psychiatrist spend the session talking about philosophy rather than providing therapeutic care. I have been systematically excluded from my daughter’s care. Reports have gone from describing me as an “over-bearing” parent, to saying I am “not taking this seriously”. I have been trying to tell services what is happening, what she and I are going through at home.

In times of crises where my daughter has been so distressed and has forgotten what she has done and said, I have recorded them to show her clinical supports. They refused to even look at it, despite me telling them how distressing the content is for me to manage. Even at the most extreme crises, including following suicide attempts, CAMHS have discharged my daughter and never offered or referred me to supports for my own wellbeing.

In the last 6 months, my daughter’s mental health has deteriorated where she is becoming violent towards me and others and has been putting herself at risk online. I had to rely on respite for 4 weeks, except the service was so underqualified that they were calling me to support them to calm my daughter down. This service and my daughter’s NDIS local area coordinator told me to “drop her daughter off at the hospital and relinquish her responsibility” because there was “no hope

This has taken a huge toll on my mental and physical health. I have had no support. When I have called the only mental health carer specific supports to provide me with referral help and information they simply couldn’t because there is nothing here for me. The good that did come out of it though is it is the only place that could understand what I was going through and could offer me one-on-one peer support. I contribute my ability to keep going in my role to this support. I can’t afford private psychology for me or my daughter because I have had to leave work, and to be able to access Carer Payment, I have had to use my reserved savings.

I have PTSD because of my own child abuse however I had gotten to a point where it was not only manageable but almost non-existent in my everyday life. Since the serious deterioration in my daughter's mental health, I have been re-traumatised, now experiencing my symptoms of PTSD. In the past 6 months, I have been recently diagnosed with functional neurological disease (FND) which my specialists have explained that severe and constant stress is associated with FND. Because of the indescribable stress, carer burnout, health deterioration, lack of supports and the feelings of utter hopelessness, I attempted to take my own life.

Attachment C - Case Study Three

I have supported my daughter who has borderline personality disorder, drug use, and Bipolar. I live in a one-bedroom apartment with my daughter because she can't afford to live on her own, and other family members have had to cut contact with her. When she is unwell, my daughter becomes vulnerable to men who want to take advantage of her. I have had to watch her in toxic relationships that have led her to behave in ways that just aren't her. She has vandalised my apartment, verbally abused me, emotionally blackmailed me, and eats all the food in my kitchen. That might sound insignificant but due to the stress, I have had to reduce my hours, I support my daughter financially as she only has a casual job and am now living from pay check to pay check.

I have responded to many suicide attempts and self-harm incidents, taking my daughter to hospital or supporting her at home when she refuses to go to hospital because of the way she has been treated. A particularly traumatic experience that led to me having to call 000. She needed medical help desperately, however, because of how heightened and distressed my daughter was police came and intervened. Watching my daughter be restrained by several police officers to get her to hospital where she so desperately needed to be, was horrific.

After this incident, I called the emergency department and asked them not to discharge her until the morning. I needed time to decompress and process what I just went through. Despite my request, an hour later my daughter was discharged and turned up at home.

I had asked a neighbour, who saw what happened with the police, to come over so I could debrief and not be alone. We had gotten take away for something to eat because of how the incident had affected me, not just emotionally and psychologically, but also physically. When my daughter walked in, she abused me verbally for calling 000 and for having a neighbour over and having something to eat. In her eyes, it looked like I didn’t care.

Attachment D – Case Study Four

My son is 31 and has schizophrenia, first diagnosed at around age 18. When thinking about help for carers, the things that occur to me are:

People often think of carers as those looking after people with physical disabilities or older people, in the same way as people with disability are often represented as being in a wheelchair or visually impaired. It would help those of us caring for someone with a mental health condition if people with disabilities were represented more broadly. This then helps people to see the role of carer as broad as well and very varied. It may not be a hands-on physical type of role and may be more off and on and require very varied responses to situations that arise. Empathy for people with mental health conditions also helps their carers.

I only recently started thinking of myself as a carer rather than a mother. I feel that it is quite important that being a carer is considered part of everyday life rather than a specific standalone role. Being a carer is something that I have morphed or blended into my life with varying degrees of intensity and stress at different times. In some ways I like to think about it as being part of my 'normal' and ongoing life. I have needed to acknowledge that it won't stop but will vary; to be prepared, but take respite when things are going ok.

The most important support for me as a carer is that my son can get the support he needs. No amount of support for me is going to help if he isn't supported.

I had no idea where to turn when he was psychotic over a period of time. There are very few services who can help at that point. The most useful and helpful people were the police and the only way this was resolved was when they managed to arrest my son for minor criminal things he was doing. This was the entry to the mental health support he needed. Every support service I called needed him to contact them for help and this wasn't going to happen.

What would have helped me was navigating the justice system, the health system and the mental health system. Plus, a decent lawyer. It has been very difficult to work out what is required for a court appearance. My son appeared in the local court in New South Wales for 7 fairly minor charges after he was released from the mental health ward in a regional hospital. The lawyer who my son found (and he applied for legal aid) did not represent my son's circumstances to the court and failed completely to submit the appropriate paperwork. This resulted in a conviction on all 7 charges, a $6,000 fine plus $2,000 court costs. We appealed this decision to the district court, and I paid for the services of a 'proper' lawyer. This has resulted in all but 3 of the charges being dropped and the remaining charges being dealt with under the mental health act - no conviction, no fine. This cost me nearly $11,000 in lawyer's fees. Complete waste of court time and money and a lot of time, stress and anxiety due to the incompetence of the original lawyer. He just didn't care.

In summary, it seems to me that what is missing is connection between services. It all seems a bit transactional with each service focussing on one part of the person. I'm left trying to connect things together for my son and he gets quite confused about why this service doesn't 'talk' to another service. In the example of the local court appearance, the magistrate had asked for my son to come back to the court with a mental health plan. The lawyer and the GP didn't seem to have any idea what was required despite this being a fairly common request (you would think). I didn't have anyone to ask, my son was left trying to navigate with two incompetent professionals, and the outcome was bad - hence the appeal.

I've had contact with various carer groups, but I think the missing thing is an agency with actual concrete knowledge - of the different systems - mental health, justice, health, Centrelink, NDIS for example. I don't really want a shoulder to cry on as such - I want concrete help when needed.

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