National Mental Health Consumer & Carer Forum

A combined national voice for mental health consumers and carers

Submission in response to the Draft Report from the Productivity Commission Inquiry into Mental Health

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National Mental Health
Consumer & Carer Forum

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The National Mental Health Consumer and Carer Forum (NMHCCF) is pleased to provide a submission in response to the Draft Report from the Productivity Commission Inquiry into Mental Health.

The National Mental Health Consumer and Carer Forum (NMHCCF) is a combined national voice for mental health consumers and carers. We listen, learn, influence and advocate in matters of mental health reform.

The NMHCCF was established in 2002 by the Australian Health Ministers' Advisory Council. It is funded through contributions from each state and territory government and the Australian Government Department of Health. It is currently auspiced by Mental Health Australia.

NMHCCF members represent mental health consumers and carers on a large number of national bodies, such as government committees and advisory groups, professional bodies and other consultative forums and events.

Members use their lived experience, understanding of the mental health system and communication skills to advocate and promote the issues and concerns of consumers and carers.

The NMHCCF acknowledges the range of issues the Productivity Commission has addressed in its Draft Report and, in particular, the focus of the recommendations on consumer-centred care.

This submission focusses on five key areas that the NMHCCF believes are important to further enhance the mental health system from a consumer and carer perspective. The five areas are:

1. Mental health carers
2. Community access and supports
3. Models of care
4. Lived experience engagement and the peer workforce
5. Lived experience peak advocacy and advisory body

Information and evidence to support the NMHCCF perspective is provided for consideration by the Productivity Commission.

We would be happy to provide any further information to support the issues raised in this submission. Please contact the NMHCCF via the Secretariat – nmhccf@mhaustralia.org or 02 6285 3100.

Yours sincerely

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1. Mental health carers

Carers are a crucial component of the mental health system. The NMHCCF believe that carers' value, roles and needs are not adequately addressed within the Draft Report.

Economic value of carers

The Draft Report provides some direction regarding carers and families in mental health but is limited to the reform objective of 'Increased support for the wellbeing and role of carers and families of people with mental illness'. While the NMHCCF supports the general direction of the recommendations related to payments for carers (Draft recommendation 13.1) and for employment support (Draft Recommendation 13.2) these recommendations are only a small component of acknowledging the value, in financial terms, of the role of carers in the mental health system.

In 2016 MIND Australia commissioned a study to investigate the economic value of mental health caring in Australia.[1] Informal mental health caring is unpaid hours of support provided by carers to people with mental illness. The findings from this study identified that:

> "It would cost $13.2 billion to replace informal mental health care with formal support services"

and for that same time period, 2015:

> "government expenditure on mental health carer services was approximately $1.2 billion"

which includes Commonwealth-funded income support payments and other Commonwealth-funded services and state and territory-funded services. These services include respite care, information, counselling and practical assistance.

A further impediment to carers is the impact of the episodic nature of mental illness which impacts on carers' abilities to obtain and maintain paid employment. Opportunities exist to change the Centrelink Mutual Obligation guidelines to incorporate voluntary work for people who are identified as providing carer support to family member experiencing mental illness. Volunteering provides an opportunity to obtain more skills, to reduce feelings of isolation, it is more flexible than paid employment, so is more achievable for the carer. Currently volunteering is only an option for those aged over 55 years.

Recommendation: Review the financial supports provided to carers of people with mental illness.

Due to the episodic nature of mental illness crisis, access to payments is a barrier. The financial burden on carers is far greater than the payments available to support them. Adequate financial support will enable carers to continue in their role.

[1] Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: summary report. Brisbane: The University of Queensland; 2016. Available at: file:///C:/Users/Julia/OneDrive%20-%20JA%20Projects%20Pty%20ltd(1)/MHA%20-%20NMHCCF/PC%20submission/The_economic_value_of_informal_mental_health_caring_in_Australia_summary_report.pdf

Carers as partners in the care team

While Draft Recommendation 13.3 considers some aspects of 'family-focused and carer-inclusive practice' the NMHCCF believes that the implementation of this recommendation will not lead to any significant changes in the involvement of carers as members of the care team.

Draft Recommendation 13.3 refers to the consideration of family and carers needs and their role in contributing to the mental health of consumers. This issue is much more complex and the recommendation does not take into account the essential role of carers as equal members of the mental health team, along with the consumer and the clinicians.

As equal members of the team, carers would not be excluded from discussions around health care plans and other decisions. Information carers have to offer the clinical team regarding issues such as a person's medical history, past diagnoses or current situation, would be sought and considered as part of the care plan.

While there may be some examples of family-centred care operating within Australia there is not a model that describes the role of the carer as an equal member of the team. The United Kingdom's NHS has developed a model, the Triangle of Care, where it is non-negotiable that services link with carers.[2]

> "The Triangle of Care is a therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing."

The Triangle of Care model was a foundation in the development of an Australian guide for working with carers of people with mental illness. [3]

The guide describes six partnership standards:

1. Carers and the essential role they play are identified at first contact, or as soon as possible thereafter.
2. Staff are carer aware and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing of information are in place.
4. Defined staff positions are allocated for carers in all service settings.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care settings.
6. A range of carer support services is available.

[2] The Triangle of Care - Carers Included: A Guide to Best Practice in Mental Health Care in England. Second Edition. Carers Trust, London 2013 Available at: file:///C:/Users/Julia/OneDrive%20-%20JA%20Projects%20Pty%20ltd(1)/MHA%20-%20NMHCCF/PC%20submission/thetriangleofcare_guidetobestpracticeinmentalhealthcare_england.pdf

[3] A practical guide for working with carers of people with mental illness, March 2016, Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia. Available at: https://livedexperienceaustralia.blob.core.windows.net/assets/PracticalGuideForWorkingWithPeopleWithAMentalIllness.pdf

These standards clearly articulate the role of carers as partners in the team and provide guidance for the implementation of this model. These partnership standards align with the Carers Recognition act 2010.[4]

Recommendation: Implement partnership models in mental health services that include carers as partners in the care team.

Carers are a crucial component of any partnership approach to service delivery and have responsibility for care when service providers are not there. Formalising the partnership model will recognise and support the role of carers and enable them to continue in their role as partners in recovery.

Support for carers

Carers and families need support structures to enable them to continue to provide the care and support they currently offer. This includes recognition of the impact of their caring role such as the need for access to respite care, impact on their capacity to work, time taken for care coordination and support and consideration of the carers capacity when care plans are made and overall support for carers and families.[5]

The NMHCCF has identified three issues of concern regarding support for carers missing from the Draft Report. The Draft Report outlines the need for adequate aftercare services following suicide attempts but does not include support for carers and family members in any postvention services. The Draft Report focusses on the role of carers in supporting children but makes no mention of the numbers of ageing carers with responsibilities for parents, spouses and family members. Finally, the Draft Report makes no recommendations regarding offering employment support services to carers to facilitate either alternative part time work or re-entry to full time work after periods out of the workforce.

Recommendation: **Implement structures that better recognise carers needs and provide support to carers.**

Recommendation: **Support a research project to consolidate the evidence base for the impact on whole families caring for a person with a mental illness, not just 'carers', in order to shape more responsive supports for families.**

The implementation of evidence-based structures that recognise and support carers would acknowledge the invaluable role of carers, identify their needs and assist them in continuing to provide their care and support without the added issue of financial and psychological distress.

[4] Carer Recognition Act 200, Available at: https://www.legislation.gov.au/Details/C2010A00123

[5] NMHCCF, 2016, NMHCCF submission to the Department of Social Services on a draft model for the delivery of carer support services. Available at: https://nmhccf.org.au/sites/default/files/docs/submission_on_dss_draft_model_for_a_new_integrated_carer_support_service_system_0.pdf

2. Community access and supports

The NMHCCF is pleased that the Productivity Commission's Draft Report acknowledges the (erroneous) perception that clinical mental health services are more important than other supports and identifies the need to enhance psychosocial supports for people with mental illness.

Good mental health is supported by:

- social inclusion
- opportunity for self-determination and control of one's life
- meaningful employment, education, income and housing
- being involved in a variety of activities
- having a valued social position
- physical and psychological security.[6]

This is especially the case for people living with mental illness.

The NMHCCF supports efforts which enhance access to community support programs that may include health, education, training, relationships, physical and creative activities. Community programs that are person-centred where active holistic support is available are especially useful.

One Australian example of such programs is the Neighbourhood Houses program in Tasmania.[7] Neighbourhood Houses are run by the community for the community and offer a wide range of programs and activities for local people to provide a sense of belonging and purpose. The Fountain House model is another example. Fountain House's vision is for people with mental illness everywhere to achieve their potential and be respected as workers, neighbors and friends. Fountain House has inspired the creation of hundreds of similar programs in 34 countries that serve more than 100,000 people annually.[8]

All community programs need to be mindful of the broad needs of their population to ensure that adequate transport is available, services and resources are relevant to the community and there is minimal financial burden for users. Meeting the needs of particular groups within the community is especially important for locally based community services. This includes ensuring services are available in rural and remote locations and services meet the needs of community groups such as people from a culturally and linguistically diverse backgrounds.

Community programs also have the potential to benefit from utilising the peer workforce as key members of their teams.

Recommendation: **Invest in community supports that meet the psychosocial needs of people living with mental illness**

The importance of access to community support services is identified as a key component in maintaining good mental health for everyone in the community and is especially important for people living with a mental illness. Barriers to access, such as transport, cost and

[6] Mental Health Commission of NSW, 2017, Available at: https://nswmentalhealthcommission.com.au/mental-health-and/the-whole-communityental
[7] Neighbourhood houses network. www.nht.org.au
[8] Fountain House: https://www.fountainhouse.org/

language, need to be addressed.

3. Models of care

The Productivity Commission's Draft Report supports the application of the stepped care model and makes several recommendations regarding the application of the stepped care model in care and service delivery. While the stepped care model professes to meet the needs of consumers the model continues to be driven by clinicians and government funding models and not consumers and carers.

The NMHCCF notes that implementation of the stepped care model in Australia has been challenging and recommends a move away from the stepped care model to a person-centred and led approach. While the stepped care model professes to be person-centred, its implementation to date as failed to provide evidence of person-centred practices, decision structures and consumer and carer participation. Any services and supports accessed must be desired and valued by consumers, and there must be real choice in clinical and psychosocial supports. No model of care is consumer-centred and led if there is no choice in what can be accessed to support recovery.

Person-centred and led approaches require that clinicians and services remain focused on the individual rather than the service. This means:

- Being aware of where the individual is at now, especially in terms of his or her journey, dreams and goals
- Matching the services or support with the person's needs rather than the other way around
- The opposite of "one-size-fits-all"
- Not fitting the person into predetermined "packages"; and
- Looking at a person's capacities and strengths and always dealing with each person as an individual.[9]

A person-centred and led approach incorporates the personal elements of the CHIME framework of connectedness, hope, identity, meaning and empowerment.[10] However it does not mean the approach is context-independent. It recognizes and responds to key relational, social and structural elements present in a person's life that are barriers to recovery, and that service planning frameworks should reflect these elements.

Recommendation: **Support the development of shared understandings of person-centred and led approaches to care and support and their implementation in a participatory environment.**

[9] NMHCCF, 2016, Advocacy Brief - Person Centred Approaches to Care and Support. Available at: https://nmhccf.org.au/sites/default/files/docs/nmhccf_-_person_centred_approaches_to_care_and_support_-_may_2016_0.pdf

[10] Slade M., Amering M., Farkas M., Hamilton B., O'Hagan M., Panther G., Perkins R., Shepherd G., Tse S., and Whitley R. Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems World Psychiatry 2014;13:12–20, Available at: https://onlinelibrary.wiley.com/doi/epdf/10.1002/wps.20084

This would include person-centred and led training opportunities and the development of person-centred and led treatment and service responses.

Consumers are not in care environments for most of their time. When consumers, carers or family members seek assistance, intervention or support, they are usually engaged in their everyday life not in care or in a clinical environment.

4. Lived experience engagement and the peer workforce

The NMHCCF strongly supports lived experience engagement, including the peer workforce, as part of mental health services and supports the Productivity Commission's recommendation to strengthen the peer workforce (Draft Recommendation 11.4). However, the NMHCCF has concerns regarding the specifics within this recommendation.

The overarching concern is that the recommendations are focused on activities being led by governments and/or the National Mental Health Commission. The NMHCCF believes that a national peer workforce organisation should be established to take the lead on the recommendations. The national peer workforce organisation would recognise the differences between the consumer and carer workforce, recommend remuneration that is fair and equitable, ensure diversity among peer workers and support the implementation and evaluation of best practice initiatives.

Another concern regards the recommendation to develop career pathways out of the peer workforce. The NMHCCF is concerned that if we encourage other career pathways that are not peer-based then we lose the values that peer work upholds. Peer work needs to be a career and profession of its own and not combined with other professions.

The NMHCCF believes that we first need to build capacity within the peer workforce and decrease high turnover, increase career pathways, establish senior peer worker positions including having lived experience representatives on government/organisation mental health committees and Boards and develop and implement a nationally agreed peer supervision framework. The NMHCCF supports the development of National Standards to be led by a national peer workforce organisation.

The NMHCCF also strongly supports an increase in lived experience-led services to complement (or replace) clinical services. The Safe Haven Café model was established in the United Kingdom. St Vincent's Hospital Melbourne established a Safe Haven Café in 2018 as an after-hours drop-in centre run by peer workers. PwC undertook an economic analysis of the café and identified a reduction in mental health related emergency department presentations to the hospital, improved patient experiences and improved social connections within the local community. PwC estimated the annual monetary benefit of the reduction in mental health-related emergency department presentations is $225,400.[11] Brook RED, is a peer-managed and operated community mental health organisation based in

[11] PwC, St Vincent's Hospital Melbourne Economic Impact of the Safe Haven Café Melbourne November 2018. Available at: https://www.thecentrehki.com.au/wp-content/uploads/2019/06/Safe-Haven-Cafe-Cost-Benefit-Analysis._FINAL.pdf

Brisbane. The services provided by Brook RED are designed to meet the varying needs of their community.[12]

The NMHCCF also supports further development of the peer workforce as part of primary care services. A study of the value of peer workers in primary care in New Zealand found that the peer workers were able to support the patient, primary health care staff and general practitioner and were skilled in navigating between primary care, specialist and hospital services.[13]

Recommendation: **Invest in the establishment of a national peer workforce organisation whose remit would include development of peer workforce standards and competencies, educational pathways and development of evidence base and research into peer workforce activities.**

Recommendation: **Support the development of lived experience-led services across primary care, mental health and community services.**

The evidence supports the value of the peer workforce and services run by people with lived experience to support recovery as the ultimate goal of care. To maximise the outcomes and impact the peer workforce a more structured approach is required, which is overseen by people with lived experience. Further, the development of lived experience-led services across the health care system will better support consumers and carers and are a financially viable proposition.

5. Lived experience peak advocacy and advisory body

The Productivity Commission has recognised the importance of consumer and carer engagement in the design of government policies and programs that affect their lives (Draft Recommendation 22.3). The NMHCCF supports the direction of this draft recommendation in that it supports the ongoing funding for consumer and carer peak bodies and reporting on funding levels. However, more structural change is required to ensure that the voice of people with lived experience of mental illness is heard in government policies and programs and services delivered by private, community and non-government organisations.

The NMHCCF calls for the establishment and running of an independent national lived experience peak advocacy and advisory body, which would comprise of both the consumer and carer voice. The lived experience peak body would support Consumer and Carer Leadership, Participation and Engagement (LPE) and Shared Decision Making (SDM), assisting with genuine co-design and co-production in reforms.

Investing in an independent national lived experience peak advocacy and advisory body would enable a robust, cohesive and supportive organisation to represent consumers and carers in advocacy at all levels. A lived experience peak advocacy and advisory body would provide an easily identifiable, respected and known source for governments and other service providers to liaise with regarding mental health policy and programs. This body

[12] https://www.brookred.org.au/about-us

[13] Perez J., and Kid J., Peer support workers: an untapped resource in primary mental health care. J PRIM HEALTH CARE. 2015;7(1):84–87. Available at: https://www.publish.csiro.au/hc/pdf/HC15084

would provide access to a legitimate and considered viewpoint representing the needs of the diversity of our population and those often under-represented. Further, the establishment of one national lived experience peak advocacy and advisory body would be a cost-effective option, with one structure, one governing body, and one set of staff.

Further, an independent national lived experience and advocacy organisation by its very nature positions itself to enable the government, departments and lead agencies to draw on lived experience to implement Productivity Commission recommendations through co-design and co-production methodologies. It is now standard Government policy in Victoria for example to avail lived experience bureaucrats to advise and co-design the Implementation Office established as part of the interim recommendations of Victoria's Royal Commission into Mental Health. This ensures contemporary practice is met, alongside community expectations for reform delivery.

Recommendation: **Establish an independent national lived experience peak body.**

There is an increasing call for consumer and carer engagement and participation across the mental health sector. The sector has also seen the growth of consumer and carer peaks and NGOs across the country. The establishment of an independent national lived experience peak body is required to ensure consumer and carer engagement is efficient and effective.