

Response to Productivity Commission Mental Health Report

Co-signatories:

Being (Consumer Advisory Group – Mental Health Inc.) is the independent NSW peak body speaking with and for people with living/lived experience of mental health issues and emotional distress. Our primary focus is to ensure the voices of people with mental health issues and emotional distress are heard by decision makers, service providers, and the community. With a long-standing history of operation Being is in a unique position to lead and influence NSW policy, legislation and service delivery, to improve the outcomes for the communities we serve.

Being has a strong human rights focus, and as such advocates for the rights of people with mental health issues and emotional distress to live and participate in the communities they choose.

Consumers of Mental Health WA (CoMHWA) is the independent mental health consumer peak organisation in Western Australia. We strengthen and advance the voice, leadership and expertise of people with lived experience of mental health issues. CoMHWA is led and staffed by people with personal experience of mental health challenges and is supported by over 1200 individual and organisational members. Through our values of inclusivity and partnership we engage people who tend to be harder to reach and work in collaboration with carers/families and service providers for mutual benefit. CoMHWA's vision is for a world where people with lived experience of mental health issues are self-directed, self-empowered, respected and connected to community.

Representation

The need for a united national mental health consumer voice is critical to ensure services/systems are meeting the diverse needs of Australians who have experienced mental health challenges.

A national system to collect and analyse consumer perspectives must be inclusive to ensure the diversity of experiences is captured. Factors such as cultural environment, homelessness, drug and alcohol issues, isolation, institutionalization, rurality and poverty can lead to under-representation and marginalization of people and their communities.

Identifying and responding appropriately to the requirements of people with lived experience of mental health issues is complex. This is exemplified in the decade it has taken for CoMHWA to successfully engage and build trust with consumers through local peer-based relationships founded on mutual respect and understanding. With over 60,000 consumer contacts last financial year CoMHWA has achieved the capacity to influence and drive mental health reform to meet the needs of Western Australians.

If the varying needs of people are not identified and addressed, then Australia risks further escalation of mental health distress and self-harm.

Recommendation 1:

A national organisation is established to provide an informed, inclusive and empowering voice for mental health consumers throughout Australia.

Consumers and Carers

There are areas of shared concern between carers and consumers where it is mutually beneficial to work collaboratively. As the peak body for mental health consumers, CoMHWA has successfully partnered with carer and/or mental health carer organisations on many occasions to address mutual issues and to develop joint submissions/reports.

However, there are matters that can be divisive and psychologically triggering between consumers and carers. Examples of potentially contentious issues observed by CoMHWA include medication compliance, suicide and self-harm, the right to privacy and personal competency.

Consumers can face stigma, discrimination and barriers to communication, relationships and problem-solving. This can create a power imbalance between carers and consumers, resulting in consumers feeling inhibited in participating and potentially being effectively silenced. There is a risk that policies and reforms may be focussed on the needs of the carer resulting in potentially compromised health outcomes for the consumer.

The amalgamation of the consumer and carer voices does not accord with the reality of circumstances for some people with personal experience of mental health issues. According to the Australian National Survey of Mental Health and Wellbeing¹, almost one-third of Australians who have psychotic disorders are living alone and 39% of these people have no 'best friend' with whom they can share thoughts and feelings. The risk of having a combined consumer and carer national organisation is the further disenfranchisement and inadequate representation of people who don't have carers which can lead to adverse impacts on their health and wellbeing.

The National Standards for Mental Health Services² recognises the right of consumers to involve or not to involve carers and others; and the right for consumers and carers to independently determine who will represent their views. The formation of a single national body for mental health consumers and carers without adequate Australia-wide consultation with consumers and carers could impinge on their respective rights to have independent voices and representation.

The potential for divergence of opinions and priorities for carers and consumers can create emotional and psychological impacts for people with lived experience of mental health issues and those who support people with personal experience of mental health challenges. The potential for harm and impacts on the capacity to be representative of a combined consumer and carer body is reflected in consumer feedback for a national organisation led by and for consumers.

It is recommended that a National Mental Health Consumer Peak Body is established to support the mental health, wellbeing and recovery of people who have lived experience of mental health issues.

To achieve consensus and mutual benefit for consumers and their carers/families/supporters, the National Mental Health Consumer Organisation would partner with national representative carers bodies such as Mental Health Carers Australia. This collaboration between consumers and carers would address mutual issues and support joint submissions/policies, whilst maintaining carer and consumer autonomy.

¹ Harvey C, Brophy L. *Medicine Today* 2011, 12(10): 73-78.

² National Mental Health Standards for Services 2010. Commonwealth of Australia.
<https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-servst10>

Recommendation 2:

An independent **National Mental Health Consumer Peak Body** is established to support the mental health, wellbeing and recovery of people who have lived experience of mental health issues.

Recommendation 3:

The National Mental Health Consumer Organisation partners with national representative carer organisation/s such as Mental Health Carers Australia to address mutual issues and support joint submissions/policies, whilst maintaining carer and consumer autonomy.

National Mental Health Consumer Model

The autonomy of a national mental health consumer organisation provides a platform to advocate for and influence what matters to mental health consumers. However, the structure of the National Consumer peak body is critical to get right to ensure it can achieve improved mental health, reduce suicide and self-harm, and improve wellbeing throughout Australia.

There is an increasing focus on the unique and critical role of individual and shared consumer perspectives to support mental health and wellbeing at a personal and community level. An independent national organisation that speaks for and by consumers to increase efficiency and effectiveness of the organisation by maximising, analysing and communicating the representative voice of the people with lived experience of mental health issues.

Past experience of attempts at establishing a national consumer organisation demonstrates the critical importance of an open and inclusive approach to facilitate representation and buy-in of the broad range of Australians with personal experience of mental health issues.

Reliance on a centralized body that is without robust connections to consumers throughout Australia is likely to fail to effectively represent them. This can lead to poorly targeted funding and policies that do not address consumer priorities and needs. Those people who are harder to engage are likely to be particularly vulnerable to be not being heard resulting in their needs being unmet and their health and wellbeing being compromised.

The leadership of state-wide consumer led organisations in a national consumer body is a vital resource to ensure equity, efficiency, effectiveness and relevance to supporting the health and wellbeing of people in Australia. This model replicates many successful national representative bodies with coalitions of state and territory peak bodies including: Community Mental Health Australia, Carers Australia, Diabetes Australia, Australian Federation of Disability Organisations, Downs Syndrome Australia and Royal Life Saving Australia.

There has been recognition by people with lived experience of mental health issues of the value of an autonomous national consumer peak body for over 7 years. At two consecutive national mental health conferences (TheMHS), the call from consumers was for a representative independent national mental health consumer organisation led by the state mental health consumer peak bodies.

The central role of the state peak mental health consumer bodies is essential to:

- Ensure a national mental health consumer organisation is informed and responsive to local voices including those who tend to be under-represented.

- Prevent duplication and inefficiency of having a national and state organisation functioning in a competitive environment.
- Facilitate equity in state and territory influence and power.
- Provide a platform to support the functioning of the national body.
- Ensure the national body benefits from local and state engagement.
- Assist state and territory organisations to support national programs and policies and the integration with state and local functions.

As the funded peak consumer bodies, Being NSW (NSW), CoMHWA (WA) and VMIAC (Victoria) formed a National Consumer Alliance in 2018. The Alliance has successfully bought the strength of over 15,000 consumer voices to contribute to national policies to better meet the needs of people with lived experience of mental health issues.

The Alliance is in the process of expanding to include mental health consumer organisations in a further three states and territories. The national consumer organisation could assist through advocacy and support with the establishment of peak bodies in states and territories where they do not exist.

Recommendation 4:

State-based mental health consumer organisations lead the National Mental Health Consumer Peak Body to support efficiency, effectiveness, validity and equity and to ensure national services/systems are meeting the diverse needs of Australians who have experienced mental health challenges.

Summary of Recommendations

1. **A national organisation is established** to provide an informed, inclusive and empowering voice for mental health consumers throughout Australia.
2. **A National Mental Health Consumer Peak Body** is established to support the mental health, wellbeing and recovery of people who have lived experience of mental health issues.
3. **The National Mental Health Consumer Organisation partners with national representative carer organisation/s** such as Mental Health Carers Australia to address mutual issues and support joint submissions/policies, whilst maintaining carer and consumer autonomy.
4. **State-based mental health consumer organisations lead the National Mental Health Consumer Peak Body** to support efficiency, effectiveness, validity and equity and to ensure national services/systems are meeting the diverse needs of Australians who have experienced mental health challenges.

Shauna Gaebler (CoMHWA)

Irene Gallagher (Being NSW)

Contact: Shauna Gaebler, CEO Consumers of Mental Health WA ceo@comhwa.org.au