National Mental Health
Consumer & Carer Forum

Submission to the Australian Government Department of Health in response to the Productivity Commission Inquiry into Mental Health Final Report

February 2021

National Mental Health Consumer & Carer Forum

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Mr Mark Roddam
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Dear Mr Roddam

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

As you are aware, the 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 many 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 Final Report and the breadth of recommendations.

The NMHCCF has focused this submission on six key areas that the NMHCCF believes are important to further enhance the mental health system from a consumer and carer perspective. The six areas are:

1. Mental health carers
2. Community access and supports
3. Models of care
4. Lived experience engagement and lived experience-led services
5. The peer workforce
6. Lived experience peak advocacy and advisory body

Information and evidence to support the NMHCCF perspective is provided for consideration by the Department of Health. A summary of relevant recommendations made by the Productivity Commission and the response from the NMHCCF is also provided.

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

Yours sincerely

Keir Saltmarsh
Consumer Co-Chair

Hayley Solich
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Summary table of recommendations from the National Mental Health Consumer and Carer Forum

Mental health carers
In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government: • Implement partnership models in mental health services that include carers as partners in the care team • Implement funded carer respite which is co-designed with carers, with a focus on these services being carer-led • Develop and implement a public campaign program to raise awareness of the Carers Recognition Act 2010 • Develop, implement and monitor programs to support families and carers with their needs and ensure the programs meet their changing needs across the lifespan of the person with a mental illness and the carer • Ensure the needs of young carers are being met, in particular as it impacts on their ongoing education, employment and relationships • Establish a dedicated MBS item for all health professionals to engage with families and carers • Mandate and support the use of the Carer Experience Survey and investigate the role of the peer workforce in its application across services • Fund a research project to consolidate the evidence base for the impact on whole families caring for a person with a mental illness, not just the identified primary carer, in order to shape more responsive supports for families.
Community supports and access
In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government: • Expands community supports to enhance consumer and carer access to health, education, training, relationships, physical and creative activities • Undertakes an evaluation on MBS-rebated psychiatric consultations • Expands the MBS sessions to enable reimbursement for supports provided by Peer Workers • Identifies and supports tools for service providers to use to obtain consumer input. • Incentivise carer engagement to address the attitude that carers are not 'core business' and therefore 'a burden' on the system's resources

Models of Care
In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government: • Supports the development of shared understandings of person-led approaches to care and support and their implementation in a participatory environment • Supports person-led training opportunities and the development of person-led treatment and service responses. Training should be undertaken through the engagement of lived experience educators to deliver person-led training as living examples of recovery • Establishes a public campaign program to raise awareness of the Carers Recognition Act 2010 • Works with states and territories to implement an education program on client privacy and confidentiality • Embraces the 'Triangle of Care' model in all services to embed carer-inclusive practices • Continues the role out of Action 27 of the Fifth National Mental Health and Suicide Prevention Plan which tasks Government to ensure that the WHO QualityRights[1] guidance and training tools pertaining to mental health are accessible to promote an awareness of consumer rights.
Lived experience engagement and lived experience-led services
In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government: • Seeks significant engagement from people with lived experience of mental ill health • Uses co-production and co-design approaches when implementing any of the recommendations within the PC Report • Funds lived experience-led services to support consumer and carer recovery.
Peer workforce
In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government: • Commits to five years funding for the peer workforce professional association to ensure the consumer and carer peer workforce professional association is sustainable beyond its establishment

[1] Further information is available at: https://www.who.int/mental_health/policy/quality_rights/en/

- Supports the development and delivery of education programs relating to the peer workforce be provided by consumer and carer peer workers led by the peer worker professional association, with engagement with States and Territories
- Supports the education programs being provided to health professionals and also offered through clinical professional associations, mental health and community services and private providers
- Implements the training programs described above at an earlier date than proposed
- Supports the implementation of the Peer Workforce Development Guidelines, Action 29 of the Fifth National Mental Health and Suicide Prevention Plan
- Supports the implementation of Action 30 of the Fifth National Mental Health and Suicide Prevention Plan.

Lived experience peak advocacy and advisory body

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Consider the establishment of a combined lived experience voice in additional to the consumer and carer peak bodies recommended
- Ensure the mechanism for the combined lived experience voice is established early in the implementation of the recommendation
- Ensure the remit of the two new bodies is in representing mental health consumers and mental health carers and families and not subsumed into more general consumer and carer peak bodies
- Ensures that the consumer and carer peak bodies are established using co-production and co-design approaches
- Ensures that the needs of mental health carers and families are specifically identified and not just adapted from work that was developed for mental health consumers
- Ensures that the annual report on the state of systemic advocacy in mental health in Australia at a State, Territory and national level captures the perspective of people with lived experience and not just the perspectives of NGOs or other organisations that represent consumers, carers and families
- Ensures that the combined voice has representation from all jurisdictions and diverse population groups such as Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse and reach into the communities they represent.

The NMHCCF has focused this submission on six key areas that the NMHCCF believes are important to further enhance the mental health system from a consumer and carer perspective. The six areas are:

1. Mental health carers
2. Community access and supports
3. Models of care
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1. Mental health carers

Productivity Commission's perspectives

The need of families and carers is addressed in Recommendation 18 of the Productivity Commission Inquiry into Mental Health Final Report (PC Report). The Productivity Commission notes that there "is scope to improve access to … supports and to improve how families and carers are included by mental health services". (p. 868).

The Productivity Commission recommendations address six issues in relation to mental health carers:

- all state and territory governments collect and report on the Carer Experience Survey
- amending the MBS to provide rebates for family and carer consultations
- enhancing workforce capacity for family- and carer-inclusive practice
- planning and funding of carer support services be the responsibility of state and territory governments
- evaluation of the effectiveness of Carer Gateway services for mental health carers
- amending the eligibility criteria for the Carer Payment and Carer Allowance to reduce barriers to access for mental health carers. (p. 868)

NMHCCF response

Families and carers provide a crucial link in the mental health system as it attempts to meet the needs of people with mental ill health. The NMHCCF acknowledges the findings outlined in the PC Report and recommendations made by the Productivity Commission. As a general

comment on the PC Report and recommendations, the NMHCCF would like to see the importance of the work of families and carers reflected throughout the entire report. Their role often is considered as 'an add on' rather than an essential part of mental health care.

Carers as partners in the care team

While Recommendation 18.1 addresses some aspects to increase support for families and carers as part of the care team, the NMHCCF believes that the implementation of this recommendation will not lead to any significant changes in the involvement of families and carers as members of the care team without development and implementation of family and carer-inclusive practices.

Families and carers need to be equal members of the team, included in discussions as part of a person-led model of care. Information carers have to offer the clinical team includes details such as a person's medical history, past diagnoses, family medical history, knowledge of what has worked in the past, what sensory plan works for the person when they are agitated or distressed, knowledge about the triggers to look for when a person shows signs of decline. Further, carers can provide useful information about their loved one's strengths and interests and insights into useful ways to work with their loved ones. It is also essential to ask carers their own views on the person and their needs and what they believe would be a useful approach. A more detailed care plan can then be developed with this knowledge and insights.

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. Families and 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 family and carer engagement strategies.

[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

3. Policy and practice protocols regarding confidentiality and sharing of information are in place.
4. Defined staff positions are allocated for families and carers in all service settings.
5. A family and carer introduction to the service and staff is available, with a relevant range of information across the care settings.
6. A range of family and carer support services is available.

These standards clearly articulate the role of families and 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]

Carers and families rely on health practitioners to provide them with information about their family member's diagnosis, the rationale for treatments and the likely outcomes. However, many health practitioners refuse to release information due to a belief that they are breaching patient privacy and confidentiality. The Carers Recognition Act, 2010, actually includes provisions that require health service providers to give carers sufficient information to assist them in their carer role.

The issue of families not being provided with sufficient information to support consumers adequately has recently been raised in the Coroner's Court in the ACT.[5] The family of Kaitlin McGill stated that they had insufficient information to assist in "facilitation of proper treatment and address her risk factors" and that this possibly contributed to her untimely death.

In the findings relating to this death, the Coroner briefly addressed the complex issues of confidentiality and privacy and recommended that:

> "*the ACT Government consult families and carers of persons subject to PTOs, as well as those subject to such orders, to explore the desirability of legislative or procedural reform about information dissemination to family and carers to support the care and treatment of persons subject to such orders.*"
>
> The Coroner also points out "*the recommendation….. is consistent with the recommendations made in the Productivity Commission's Mental Health Inquiry Report, Volume 1, No. 95 (30 June 2020) and in particular:*
>
> *(a) the expressed aim for a person-centred mental health system the features of which include "[participation of the consumer's family or carer actively sought to add to the value and effectiveness of the clinical or support service;"] and*

[4] Carer Recognition Act 2010, Available at: https://www.legislation.gov.au/Details/C2010A00123

[5] ACT Coroner's Court, Findings into the death of Kaitlin O'Keefe McGill, Citation [2020]CD7, Died March 2016, Coroner Morrison's Findings made on 10 December 2020. https://courts.act.gov.au/magistrates/decisions/inquest-into-death-of-kaitlin-okeefe-mcgill

(b) embracing the concept of the personal recovery of an individual within their family, carer, community and cultural context, rather than a narrow focus on clinical recovery — as endorsed by Australian health ministers".

Education for health services providers on the Carer Recognition Act 2010 is required to address the misconception regarding privacy and confidentiality and other actions put in place to ensure carers and families receive the information required for them to undertake their role.

The NMHCCF is concerned that Recommendation 5, and specifically Action 5.3 in the PC Report (p. 64) has the potential to exclude carers and families from being part of the care team if wellbeing of school aged children is to be led through the school system. The implementation of this action needs to clearly articulate the roles and responsibilities of carers and families, as well as any existing health and community services to avoid establishing a mechanism in one silo while one operates within another silo.

Support for families and carers

The Productivity Commission appear to have focused primarily on the consumer's right to recovery and support and failed to articulate the equal right that carers and families have to recovery of their own lives.

The NMHCCF acknowledges the need for a range of support services for families and carers, as outlined in *A practical guide for working with carers of people with mental illness.*[6]

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.[7]

The NMHCCF recommends investigating and removing the barriers to full citizenship for carers. Barriers to full citizenship for carers needs to go beyond just understanding what they are. There needs to be a comprehensive plan of how we can remove these barriers. *The Practical Guide to Working with Carers of People with a Mental Illness* is the first step in addressing barriers at service-level. This does not address the barriers some carers face of

[6] A practical guide for working with carers of people with a 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://mhaustralia.org/publication/practical-guide-working-people-mental-illness

[7] 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

the impacts of caring on their own mental health, the lack of vision of how their lives could be transformed and the lack of services that can support carers who are in the process of recovery. Programs like WellWays "Building a Better Future" program[8] are effective at creating awareness and helping to shift families. However, this is just one program, trained in a few organisations in a few states. There is a need for a national approach to removing barriers for carers with focused attention and activity. And unfortunately, in its current format the Carer Gateway program is not going to produce the desired results, because it is too broad in its focus. Mental health carers have quite unique support needs that differentiate them from other disabilities carers. Psycho-social disability carers require specialised support and recovery services, if we want carers to be productive members of the community as the PC Report suggests.

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) Position Paper on 'Supporting carers in the mental health system'[9] describes well the challenges and barriers that carers and families face in supporting people with lived experience of mental ill health.

The NMHCCF identifies the need for respite for families and carers is critical. While the PC Report makes multiple references to carer respite, including the historical reasons there is no directly funded carer respite in Australia today, there are no recommendations for respite services.

Families and carers need a rest from the demanding and enduring duties of being a dedicated resource to a loved one. There are significant demands on families and carers in terms of emotional, social, physical and psychological needs and carers require respite that is appropriately funded. In doing so carers should be consulted about their needs so that a funded respite program is co-designed and not developed without families and carers in the design process. The ideal model would involve carers and families accessing carer-led respite services.

The RANZCP Position Paper on 'Supporting carers in the mental health system' has a focus on the issues for specific groups of carers, such as young carers, older carer and carers of older people, carers in Indigenous communities and for people from CALD communities.

Some examples to illustrate this point are provided below.

- An aged carer will not have as a priority finding employment to fit around their caring responsibilities. However, they will be greatly stressed by what the future holds for themselves as retirees and their adult child after they are no longer able to provide care and support for their ill child.

[8] https://www.wellways.org/our-services/building-future

[9] RANZCP Position Paper 76 - Supporting carers in the mental health system, 2012. Available at: https://www.ranzcp.org/news-policy/policy-and-advocacy/position-statements/supporting-carers-in-the-mental-health-system

- A parent of teenagers whose life may be intermittently interrupted by the episodes of anxiety or depression of their teenager, may not have as a priority in their mind how they are going to live off their greatly diminished super because they can't hold down a job. They may have had to leave work because of their priority to support their child. They may be looking for ways to re-enter the workforce but need supportive employers and graduated return to work options.

- That young person who is providing support to their sibling may need support, reasonable adjustments and financial assistance to engage in skills and knowledge development, so they don't fall behind their peers.

It is imperative that health care providers recognise, acknowledge and respond to the issues faced by all carers and families and assist them in undertaking their carer role in addition to supporting them to fulfil their own lives. This may require funded engagement.

Some further examples where families and carers have specific support needs include:

- access to aftercare services following a family members suicide attempts
- capacity to access independent legal representation when families and carers interact with the legal system; for example, when a family member is detained, is under a treatment order, or when families are involved in coronial proceedings
- flexible services that meet the needs of families and carers across the lifespan of the person with mental ill health, and, also across their own lifespan
- more focus on emotional, physical and financial supports for families and carers.

The NMHCCF has identified two examples of programs that are designed to meet the support needs of families and carers which provide guidance to the Department of Health in implementing the recommendations in the PC Report:

  - Families where a Parent has a Mental Illness (FaPMI) operating in Victoria[10]

  - A Peer Recovery support program for families and carers is operating in Western Australia[11]

In summary, for carers to continue to care and to become full citizens there are barriers that need to be identified and shifted. These barriers exist within the community because of stigma, within services because of cultures that are not inclusive and in the carers themselves because of the trauma and helplessness they often feel because of being 'trapped' in their care for their loved one. Respite for carers that is restorative, not just a replacement of care, is required. Retreats which previously were conduits of hope, education and connection for mental health carers need to be returned, as well as other respite options.

[10] https://www.bouverie.org.au/images/uploads/FaPMI_Program_Guidelines_FINAL.pdf
[11] model-3-peer-recovery-print-100-.pdf (waamh.org.au)

Carers, which are essentially the family and friends of people with a mental illness matter. They contribute significantly to reducing the burden of care on the community. They deserve recognition, support and opportunity just like any other community member.

NMHCCF recommendations

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Implement partnership models in mental health services that include carers as partners in the care team
- Implement funded carer respite which is co-designed with carers, with a focus on these services being carer-led
- Develop and implement a public campaign program to raise awareness of the Carers Recognition Act 2010
- Develop, implement and monitor programs to support families and carers with their needs and ensure the programs meet their changing needs across the lifespan of the person with a mental illness and the carer
- Ensure the needs of young carers are being met, in particular as it impacts on their ongoing education, employment and relationships
- Establish a dedicated MBS item for all health professionals to engage with families and carers
- Mandate and support the use of the Carer Experience Survey and investigate the role of the peer workforce in its application across services
- Fund a research project to consolidate the evidence base for the impact on whole families caring for a person with a mental illness, not just the identified primary carer, in order to shape more responsive supports for families

2. Community access and supports

Productivity Commission's perspective

The PC Report identified that:

> "a person-centred mental health system would comprise the full spectrum of community support and clinical services people may need to recover from mental ill-health and live healthy, productive lives. Consumers and carers should be able to access the services they need when they need them, regardless of administrative or funding structures underpinning them. Wherever possible, such services would reflect the cultural, social and clinical preferences of the consumer.
>
> Services should be delivered by a skilled workforce, supported by technology and comprehensive governance arrangements, to ensure that they are responsive to local needs and can be readily ramped up and down as needs change" (p. 166)

The recommendations that address this finding and are most relevant to community support and access are found in Recommendation 12 - Address the Healthcare Gaps: Community Mental Healthcare and Recommendation 17 – Psychosocial Supports. The findings supporting both recommendations acknowledge the gaps that have been created through the lack of cross-sectoral arrangements.

Actions within Recommendation 12 support a rigorous evaluation of MBS-rebated psychological therapy, increased funding for community ambulatory services, improve access to low-intensity mental health treatments and permanent changes to expand access to psychological therapy and psychiatric treatment by videoconference and telephone that were introduced during the COVID-19 crisis. (p. 524)

When discussing psychosocial supports the Productivity Commission acknowledges the "inefficient funding arrangements and service gaps" and that this "is affecting the recovery of people with mental illness and their families, who can benefit substantially from improved access to psychosocial supports". (p. 826) The actions are focused on the provision of psychosocial support, be it through the National Disability Insurance Scheme (NDIS) or from services funded by States and Territories.

As an enabler of change Action 22.3 of the PC Report states that "All Governments should commit to a nationally consistent whole-of-government approach to prevention, early intervention and recovery in mental health". (p. 1110)

NMHCCF response

The NMHCCF is pleased that the Productivity Commission has identified the many challenges for people with mental ill health and their families and carers in accessing community supports and recognised that 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.[12]

While the NMHCCF supports the relevant recommendations proposed in the PC Report the Forum recommends that more be done to address the social and emotional wellbeing of all people and especially the psychosocial and community support needs of people with lived experience of mental illness, including families and carers. This requires all governments to address the gaps in community mental health care while also focusing on the broader community system as a whole to support the recovery focus.

The NMHCCF supports efforts which enhance access to community supports 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 required. Crucial issues to be addressed through holistic community supports are poverty and homelessness.

It is important too that these community support programs are not just targeted at the needs of people with low-intensity mental illness. The results from the Survey of High Impact Psychosis identified that:

> "*Money, social engagement and employment are the most important challenges for people with psychotic illness, as well as good physical and mental health. An integrated approach to recovery is needed to optimise service delivery and augment evidence-based clinical practice with measures to improve physical health and social circumstances. Meeting these challenges has the potential to reduce costs to government and society, as well as promote recovery*."[13]

Governments are tasked with expansion of community mental health, with a focus on non-clinical elements of community support. All community programs need to consider the broad needs of their population to ensure that adequate transport is available, resources provided are relevant to the specific community and there is minimal financial burden for users.

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[12] Mental Health Commission of NSW, 2017, Available at: https://nswmentalhealthcommission.com.au/mental-health-and/the-whole-communityental

[13] Morgan VA, Waterreus A, et al, Responding to challenges for people with psychotic illness: Updated evidence from the Survey of High Impact Psychosis. Aust N Z J Psychiatry. 2017 Feb;51(2):124-140. doi: 0.1177/0004867416679738. Epub 2016 Dec 5. PMID: 27913580. Available at: https://pubmed.ncbi.nlm.nih.gov/27913580/

Meeting the needs of particular groups within the community is especially important for locally based community resources. This includes ensuring supports and resources are available in rural and remote locations and that they meet the needs of community groups such as people from a culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds.

One example of an innovative community-based program is operating in Western Australia. The Individualised Community Living Strategy, is a partnership across a range of community and health agencies to provide coordinated clinical and psychosocial supports to assist eligible individuals to achieve their recovery goals and live well in the community.[14]

There is a need for more variety in supports that consumers and families and carers can access, including more lived experience-led supports (both consumer and carer led) as described on pp 22-26. Some of these supports may be provided by peer workers. The role of Peer Workers in supporting community resources and links to mental health services is described at pp. 27-32.

Consumers need to be able to access the supports and resources they need which may involve a brokerage model to ensure supports are matched to the consumer need. Further, there is a need to build a funded, robust and sustainable community support sector with sound structures and processes that meet community need. Several former Australian Government initiatives such as Partners in Recovery (PIR) and Personal Helpers and Mentors (PHaMs) have elements which provide useful examples of supports for addressing the community support needs of people.

The NMHCCF agrees to the availability of supports provided via telehealth, but not as a method of choice and not the only mechanisms for consumers, families and carers to access mental health and community supports. Telehealth services are particularly useful for enabling access in rural and remote locations where access to providers may be limited. The NMHCCF notes though the technological and class divide for people with lived experience of mental ill health. Videoconference assumes technological literacy, hardware and purchased data and many consumers, carers and families may not have access to any, or all, of these things.

Further, it was discovered through the pandemic where services moved to telehealth as the only option for service delivery, that there were both positive and negative experiences from a carer perspective. Carers appreciated the convenience of a phone call to the person they were caring for as it meant less effort required and time spent per appointment, but they also experienced being left outside of the communication loop. One carer reported: "*I had people turn up at my door who I didn't know or expect. My partner was discharged from the service without any consultation and I know that he needs a medications review*."

[14] More information available at: https://www.mhc.wa.gov.au/media/2791/guidelines-individualised-community-living-strategy-guidelines-2018.pdf

Telehealth options should be supported by intentional communications to update carers on any plans or changes in treatment regimes.

The NMHCCF also recommends consumer input is regularly sought by providers. The NMHCCF supports the use of reliable tools for this task. Two specific tools are:

- the Measure of Citizenship Among Persons with Mental Illnesses[15,16] developed by researchers at Yale University. This tool measures a person's connections to the "5 Rs" of rights, responsibilities, roles, resources, and relationships in addition to the need for a sense of belonging in one's community and in society.
- the Session Rating Scale, by Scott Miller.[17] This tool asks the client to rate the benefit of the treatment and their 'fit' with the provider which would be beneficial for all parties.

Other comments from the NMHCCF regarding the relevant recommendations focused on community supports and access include:

- support for the recommendation that the Government commission an evaluation of MBS-rebated psychological therapy (Action 12.3) while also recommending that an evaluation also needs to be completed for MBS-rebated psychiatric consultations
- recommending the expansion of MBS sessions for supports provided by Peer Workers
- support clients having more than 10 sessions per calendar year to see a psychologist. The number of client sessions per year needs to be based on clinical need, not an arbitrary figure.

Recommendations to enhance community supports

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Expands community supports to enhance consumer and carer access to health, education, training, relationships, physical and creative activities
- Undertakes an evaluation on MBS-rebated psychiatric consultations
- Expands the MBS sessions to enable reimbursement for supports provided by Peer Workers
- Identifies and supports tools for service providers to use to obtain consumer input
- Incentivise carer engagement to address the attitude that carers are not 'core business' and therefore 'a burden' on the system's resources.

[15] https://projectcitizenship.com/citizenship-mental-health/

[16] O'Connell MJ, Clayton A, Rowe M. Reliability and Validity of a Newly Developed Measure of Citizenship Among Persons with Mental Illnesses. Community Ment Health J. 2017 Apr;53(3):367-374. doi: 10.1007/s10597-016-0054-y. Epub 2016 Oct 6. PMID: 27714484. https://pubmed.ncbi.nlm.nih.gov/27714484/

[17] Available at: https://www.scottdmiller.com/wp-content/uploads/documents/SessionRatingScale-JBTv3n1.pdf

3. Models of care

Productivity Commission's perspectives

The PC Report has identified that the "Australian mental health system should be person-centred, supporting prevention by reducing the risk of an individual developing mental ill-health and enabling early intervention if mental illness develops". (p. 166). The PC Report identifies in Recommendation 4 that:

"Governments should create a mental health system that places people at its centre. The needs, preferences and aspirations of the people who use the system, as well as their families and carers, should shape all parts of a person-centred system — from the work of the individual clinician to the policies proposed by decision makers — to create recovery-oriented services and supports". (p. 63)

Recommendations throughout the PC Report have a focus on the person-centred approach and enablers of a person-centred mental health system are identified, including workforce, technology, funding and governance mechanisms, and data to improve outcomes. (p. 188 – 190)

NMHCCF response

The NMHCCF is pleased to see that the Productivity Commission has progressed from the direction of its Draft Report where it advocated for the application of the stepped care model in mental health care and service delivery. The NMHCCF notes the shift to a person-centred approach to care and recognises there is little guidance on models of care or pathways for clinicians, services or individuals to use.

For many years the concept of person-centred care has become embedded as a feature of mental health care planning. The NMHCCF is concerned that there is still no widespread agreement regarding how 'person-centred' is defined or how it can guide the delivery of services. There are now many guidelines and frameworks across jurisdictions and community managed mental health services, but consumers and families and carers are reporting services frequently do not quite hit the mark. Many clinicians and service providers translate person-centred to providing 'the best' care to an individual with this care being decided by 'professionals' with some consumer input. As one researcher puts it:

> *"It is not clear, however, that services attend to patient values and preferences as closely as they should. Terms such as 'treatment- resistant' and 'non-compliant' seem to belie an attitude where the therapist's opinion is privileged rather than the patients*."[18]

[18] Timothy A Carey (2016), Beyond patient-centered care: Enhancing the patient experience in mental health services through patient-perspective care, Patient Experience Journal: Volume 3, Issue 2 Article 8, https://pxjournal.org/journal/vol3/iss2/8

Person-centred is intended to mean providing care to meet the needs of individual consumers in a sensitive, genuine and responsive way, putting in place systems of support that will be recovery-oriented and which promote and respect self-determination. Often the self-determination perspective is not fully understood or recognised, and instead, the opinions of consumers are noted without a full exploration of what individuals, families and carers really want.

Person-led, on the other hand, is unambiguous, placing the consumer in the driver's seat, directing their individual journey based on their needs and choices with support from family and carers, clinicians and service providers. A person-led approach is one in which clinicians and managers understand that decisions are defined by the person, not the provider.

The NMHCCF recommends that a person-led model of care is at the centre of any actions arising from the PC Report. 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. Community assertive outreach is one example of a person-led approach to service delivery.

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

- respecting where the individual is at now, their journey, dreams and goals
- matching the services and support with the person's needs, which may be from outside the mental health system
- working in partnership with the individual, family and carers to ascertain a person's capacities and strengths.[19]

A person-led approach has a broader focus than just the mental health care system. A person-led approach incorporates the personal elements of the CHIME framework of connectedness, hope, identity, meaning and empowerment.[20] However it does not mean the approach is context-independent. It recognises 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. 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.

[19] NMHCCF, 2021, Advocacy Brief – Transforming 'Person-Centred' to 'Person-Led' approaches (in publication). Available at: www.nmhccf.org.au

[20] 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

Some specific issues identified by the NMHCCF in reviewing the findings and recommendations in the PC Report for the consideration of the Department of Health are:

- the severe lack of coordination between service providers is a significant gap in any model of care. While Action 9 of the Fifth National Mental Health and Suicide Prevention Plan tasks Governments to develop, implement and monitor national guidelines to improve service coordination, the action is still based on a mental health model rather than a person-led, whole of service model that includes consumers, families and carers and services providers from across the mental health and community sectors

- the gaps in service coordination are very apparent in discharge planning when follow-up or referral to other agencies are not planned and result in poorer outcomes including re-admission to hospital. Active engagement with consumer and career peer workers would enhance service coordination

- the gaps in service coordination are exacerbated by a significant lack of understanding of confidentiality where service providers are unsure of the limits of their information sharing with carers and families

- there is virtually no understanding of the Carers Recognition Act 2010

- there is a need to develop a model for remuneration for service providers to attend case conferences, rather than working in silos. The client and their family should be able to decide who attends these case conferences, and there needs to be funding for one specific worker to be the main coordinator

- commissioning needs to fund integration of mental health and Alcohol and Other Drug (AOD services). For example, staff with both mental health/AOD expertise, co-location of staff, no wrong door for individuals and the like. This applies to the Australian Government and Primary Health Networks (and other commissioning bodies). The First Step program operating in Victoria provide a useful model for consideration by the Department of Health.21 First Step provides an addiction and mental health outpatient clinic with a multi-disciplinary team specialises in supporting people with complex needs, those at risk of hospitalisation for their mental health, imprisonment, homelessness, or worse

- as described elsewhere in the PC Report, there is a need for increased numbers of peer workers and increase participation by the peer workforce in a person-led approach

- there is a need for understanding of different cultures and the impact on decisions made by consumers, carers and families as a result of culture. Access to Traditional Healers is an example of a service meeting the specific needs of people from an Aboriginal or Torres Strait Islander background

- there is a need for mechanisms that ensure accountability within the private sector in line with expectations in the public sector.

[21] Further information available at: https://www.firststep.org.au/

NMHCCF Recommendations

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Supports the development of shared understandings of person-led approaches to care and support and their implementation in a participatory environment
- Supports person-led training opportunities and the development of person-led treatment and service responses. Training should be undertaken through the engagement of lived experience educators to deliver person-led training as living examples of recovery
- Establishes a public campaign program to raise awareness of the Carers Recognition Act 2010
- Works with states and territories to implement an education program on client privacy and confidentiality
- Embraces the 'Triangle of Care' model in all services to embed carer-inclusive practices
- Continues the role out of Action 27 of the Fifth National Mental Health and Suicide Prevention Plan which tasks Government to ensure that the WHO QualityRights[22] guidance and training tools pertaining to mental health are accessible to promote an awareness of consumer rights.

[22] Further information is available at: https://www.who.int/mental_health/policy/quality_rights/en/

4. Lived experience engagement and lived experience-led services

Productivity Commission's perspective

The Productivity Commission has recognised the importance of consumer and carer engagement in the design of government policies and programs that affect their lives. (p 1113)

The PC Report recommends the development and implementation of person-centred care, noting that "Consumers and carers should be able to access the services they need when they need them, regardless of administrative or funding structures underpinning them. Wherever possible, such services would reflect the cultural, social and clinical preferences of the consumer". (p. 116)

NMHCCF response

The NMHCCF response addresses two aspects of lived experience:

- lived experience engagement and,
- lived experience-led services.

<u>The NMHCCF Lived experience engagement</u>

The concept of lived experience engagement is not a new one within mental health policy and planning. The National Mental Health Policy[23], published in 2009, acknowledged that consumers, carers and families should be partners in planning and decision-making and should be at the centre of, and enabled to take an active role, in shaping the way in which services are planned, delivered and evaluated.

However, there are too few examples of robust lived experience engagement in co-production and co-design of mental health and community sector policy, planning, service delivery and evaluation. As Grace Tame said so eloquently in her 2021 Australian of the Year speech:

"Lived experience informs structural and social change"

This 'structural and social change' will only come about if governments and private sector organisations genuinely commit to developing and maintaining organisation cultures that value the voice of people with lived experience and engage them in meaningful ways through co-production and co-design.

Throughout the PC Report there is little detail on how the recommended person-centred approaches to care should be developed, delivered or evaluated and there are no references to co-production or co-design by people with lived experience of mental ill health.

[23] National Mental Health Policy, 2009, Australian Government

The NMHCCF recommends that a co-production and co-design approach be followed when implementing any of the recommendations within the PC Report.

The following definitions articulated by the NMHCCF[24] are provided to ensure agreed understanding of these terms.

> Co-Design: Identifying and creating an entirely new plan, initiative or service, that is successful, sustainable and cost-effective, and reflects the needs, expectations and requirements of all those who participated in, and will be affected by the plan.
>
> Co-Production: Implementing, delivering and evaluating supports, systems and services, where consumers, carers and professionals work in an equal and reciprocal relationship, with shared power and responsibilities, to achieve positive change and improved outcomes.

For governments and service providers to plan and deliver services that " …reflect the cultural, social and clinical preferences of the consumer" (PC Report, p. 116) a trauma-informed recovery-oriented approach is required.

This approach truly supports a person-centred way of working as it requires "sensitivity to individuals' particular needs, preferences, safety, vulnerabilities and wellbeing, recognises lived experience and empowers people with lived experience to genuinely participate in decision-making".[25]

The trauma-informed recovery-oriented approach means that "services are aware of and sensitive to the dynamics of trauma as distinct from directly treating trauma per se".[26] A trauma-informed recovery-oriented approach needs a supportive culture where lived experience engagement is considered critical to successful planning, policy, service delivery and evaluation. Trauma informed recovery-oriented approaches to policy and support provides for empathetic, kind, and compassionate care. One element of the culture is evidenced though education programs being provided by people with lived experience.

The figure below depicts a model defining the levels of lived experience participation.[27]

[24] Further information on these approaches is available on the NMHHCF website: https://nmhccf.org.au/resources/publications?sort_by=title&sort_order=ASC&f%5B0%5D=field_publication_type%3A106

[25] Recovery Oriented Language Guide - Second Edition Revised, Mental Health Coordinating Council 2018

[26] Recovery Oriented Language Guide - Second Edition Revised, Mental Health Coordinating Council 2018

[27] University Hospitals of Leicester NHS Trust, Patient and Public Involvement Strategy, June 2019, Available at: http://www.library.leicestershospitals.nhs.uk/pubscheme/Documents/How%20we%20make%20decisions/Board%20Papers/(2019)%20-%20Thursday%206%20June%202019/paper%20G.pdf

Figure 1: Levels of lived experience engagement

Level of participation		Elements of this participation	What does it mean
1	**Consumer- and carer-led**	Consumers, carers and families set priorities, lead major activities and drive the organisation to meet its objectives	People doing it **for themselves**
2	**Co-Production**	Consumers, carers and families are equal partners in the design, implementation and evaluation. Equal influence over decisions	Doing it **with** people
3	**Co-Design**	Consumers, carers and families are partners in the policies and programs with significant influence over decisions	
4	**Meaningful engagement**	Consumers, carers and families engaged to influence policy and program direction but are not decision makers	Doing it **for** consumers and carers
5	**Peripheral engagement**	Consumers, carers and families are involved in policy development and projects but have limited ability to influence outcomes	
6	**Consulting**	Consumers, carers and families views are sought but may have no influence over decisions	
7	**Informing**	Consumers, carers and families views are not sought. There is one way communication about policies and programs	Doing **to** consumers and carers
8	**Excluding**	Consumers, carers and families are excluded services, systems or decisions	Excluding

Source: Adapted by the NMHCCF from the University Hospitals of Leicester NHS Trust, Patient and Public Involvement Strategy, June 2019,

All too often in government initiatives the participation of people with lived experience occurs at the engage, consult and inform levels. The NMHCCF recommends that in implementing the

recommendations of the PC Report all governments move their approach to the co-production, co-design and lived experience led levels of participation and engagement.

Using co-design and co-production approaches will take courage from governments as the approach requires that the process starts from a blank slate and the resourcing and timelines are developed as the group works through the issues. To support this direction the NMHCCF recommends the introduction of co-design and co-productions training by lived experience educators.

Three examples where lived-experience engagement would be invaluable to gain further knowledge and understanding of issues and develop person-centred approaches are described below.

Suicide prevention

There are opportunities through lived experience engagement, using co-production and co-design approaches, to connect with people with lived experience of suicidality to gain greater insights into the issues – as individuals or in specific communities such as those living in rural and remote locations, people from culturally and linguistically diverse backgrounds.

Telehealth services

While telehealth services have been sought after by the community there is an assumption that people have the resources they need for the use of telehealth, such as hardware, data, secure internet services and a safe environment to participate in telehealth services. Data is a huge issue and the costs associated with it have been overlooked. For some there is anxiety around using these services while others have taken to them readily.

Broad lived experience engagement to discuss the pros and cons of telehealth services would be a valuable mechanism to find out what different people, in different communities, think about the services.

Feedback/complaints mechanisms

Access to robust complaints systems for people with lived experience are required. The PC Report recommends action to develop a simpler and more transparent complaints system (Action 22.5, p. 1114). Any action to develop such a complaints system must involve co-production and co-design with people with lived experience.

Lived-experience led services

The NMHCCF supports the direction of the PC Report in promoting person-centred models of care. However, these models continue to be primarily focussed on delivery by clinical teams within the mental health or community sectors. The NMHCCF strongly supports the continued development of lived experience-led services across primary care, mental health and community services to complement (or replace) clinical services.

In our submission to the PC Interim Report the NMHCCF highlighted two particular programs which are again described below.

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.[28]

Brook RED, is a peer-managed and operated community mental health organisation based in Brisbane. The services provided by Brook RED are designed to meet the varying needs of their community.[29]

The Interim Report of the Royal Commission into Victoria's Mental Health System also identified other lived experience-led programs which demonstrate the type and outcome of the service:[30]

- *The Peer Operated Service in Hervey Bay, Queensland.* Delivered by Flourish Australia, services provided include a resource centre where people can involve themselves in one-on-one support or group activities, a phone line and a rest and recovery house. The service is delivered by peer support workers and volunteers, all of whom have lived experience.
- *Expanding Post Discharge Support, Victoria.* This program offers tailored outreach support to people in their home immediately following discharge from a public specialist clinical mental health service, delivered by consumer and carer peer support workers. The peer support workers make a minimum of three contacts in the first 28 days after discharge.

NMHCCF Recommendations

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Seeks significant engagement from people with lived experience of mental ill health
- Uses co-production and co-design approaches when implementing any of the recommendations within the PC Report
- Funds lived experience-led services to support consumer and carer recovery.

[28] 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

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

[30] Royal Commission into Victoria's Mental Health System Interim Report, November 2019, p.496

5. The Peer Workforce

Productivity Commission's perspective

The Productivity Commission recognises the value of the peer workforce and the current under-utilisation of peer workers as part of the mental health workforce.

The recommendations outlined in the PC Report addressing peer workforce task the Australian Government with strengthening "the peer workforce by providing once-off, seed funding to create a professional association for peer workers, and in collaboration with State and Territory Governments, develop a program to educate health professionals about the role and value of peer workers in improving outcomes". (Action 16.5, p 732)

The PC Report describes peer workers roles, obstacles to their use (p. 724 – 732) and outlines their work as part of family and carer workforces (p. 899).

The Productivity Commission made additional references to mental health workforce planning, especially via the National Mental Health Workforce Strategy that is being developed by the Australian Government.

NMHCCF response

The NMHCCF welcomes the recommendations made in the PC Report regarding peer workers and the peer workforce and recognises the challenges that remain to ensure a viable, efficient and effective peer workforce operates within Australia. However, the recommendations do not go far enough to ensure organisations culture, training and development, human resource structures and processes are in place to support the peer workforce.

The Interim Findings of the Royal Commission into the Victorian Mental Health System have described well the perception of the NMHCCF regarding peer workers and the peer workforce (p. 514):

> "…..members of lived experience workforces face a number of structural challenges that impinge on their ability to be as effective as possible. The principal challenges are:[31]
>
> - lack of organisational support and leadership
> - limited access to (peer) supervision
> - unclear roles and responsibilities
> - workers not feeling valued in their roles
> - mental health stigma
> - inadequate remuneration

[31] Royal Commission into Victoria's Mental Health System Interim Report, November 2019

- the limited number of full-time positions and career opportunities, particularly in leadership roles
- the burden of being a 'lone worker'."

The NMHCCF strongly supports the need for structures such as a professional association, workforce planning to identify paid positions for both consumer and carer peer workers, education and training for peer workers, professional peer supervision programs and education for other health professionals. Additionally, culture and organisational readiness is critical to the peer workforce being able to achieve the desired outcomes for clients.

Professional association for peer workers

The NMHCCF welcomes the recommendations made in the PC Report regarding peer workers and the peer workforce. The NMHCCF is pleased to see that the recommendations described in the Draft Report which were focused on activities being primarily led by governments and/or the National Mental Health Commission have been changed to being led by a national peer workforce organisation.

However, the NMHCCF is concerned that the Australian Government is only being tasked with providing once-off, seed funding to create the professional association. The establishment of a professional association will take time and will require financial support for a period of time as it develops its workplan and membership base.

The NMHCCF believes that the role of the consumer and carer peer workforce professional association would include:

- development of consumer and carer peer worker role delineation
- develop and implement peer supervision pathways for consumer and carer peer workers
- data collection at both national and jurisdictional levels, supporting planning, training and peer supervision of the consumer and carer peer workforce
- development of training programs for other members of the mental health workforce especially with a focus on enhancing workplace culture to support consumer and carer peer workers.

The national consumer and carer peer workforce association would provide significant value to the mental health and community sectors by undertaking work to:

- recognise the differences between the consumer and carer peer workforce
- recommend remuneration that is fair and equitable
- ensure diversity among consumer and carer peer workers, and
- support the implementation and evaluation of best practice initiatives.

Further, a consumer and carer peer workforce professional association would:

- 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 the national consumer and carer peer workforce association.

The PC Report describes the work of the Private Mental Health Consumer Carer Network (now Lived Experience Australia), funded by the National Mental Health Commission to undertake work to investigate the feasibility of establishing a member-based organisation for the peer workforce in Australia.[32]

Education for health professionals on the role and value of peer workers

The NMHCCF supports the need for education programs to "educate health professionals about the role and value of peer workers in improving outcomes" (Action 16.5, p 732). The Forum also recommends that education programs should be provided by consumer and carer peer workers and offered through clinical professional associations, mental health and community services and private providers. The NMHCCF believes that this work should be led by the peer worker professional association, with engagement with States and Territories, rather than being led by government. Key stakeholders would be part of any training program development.

The NMHCCF does not support this activity commencing later in the implementation of the PC Report recommendations as the education of health professionals is key to developing the supportive and responsive culture that is required across the mental health sector to enable peer workers to be effective in their work.

Mental health workforce planning and the peer workforce

The PC Report relies on the National Mental Health Workforce Strategy as they key driver of workforce planning. The NMHCCF has been involved as members of Working Groups in the development of the National Mental Health Workforce Strategy and is generally supportive of the direction of the Strategy, especially regarding the peer workforce.

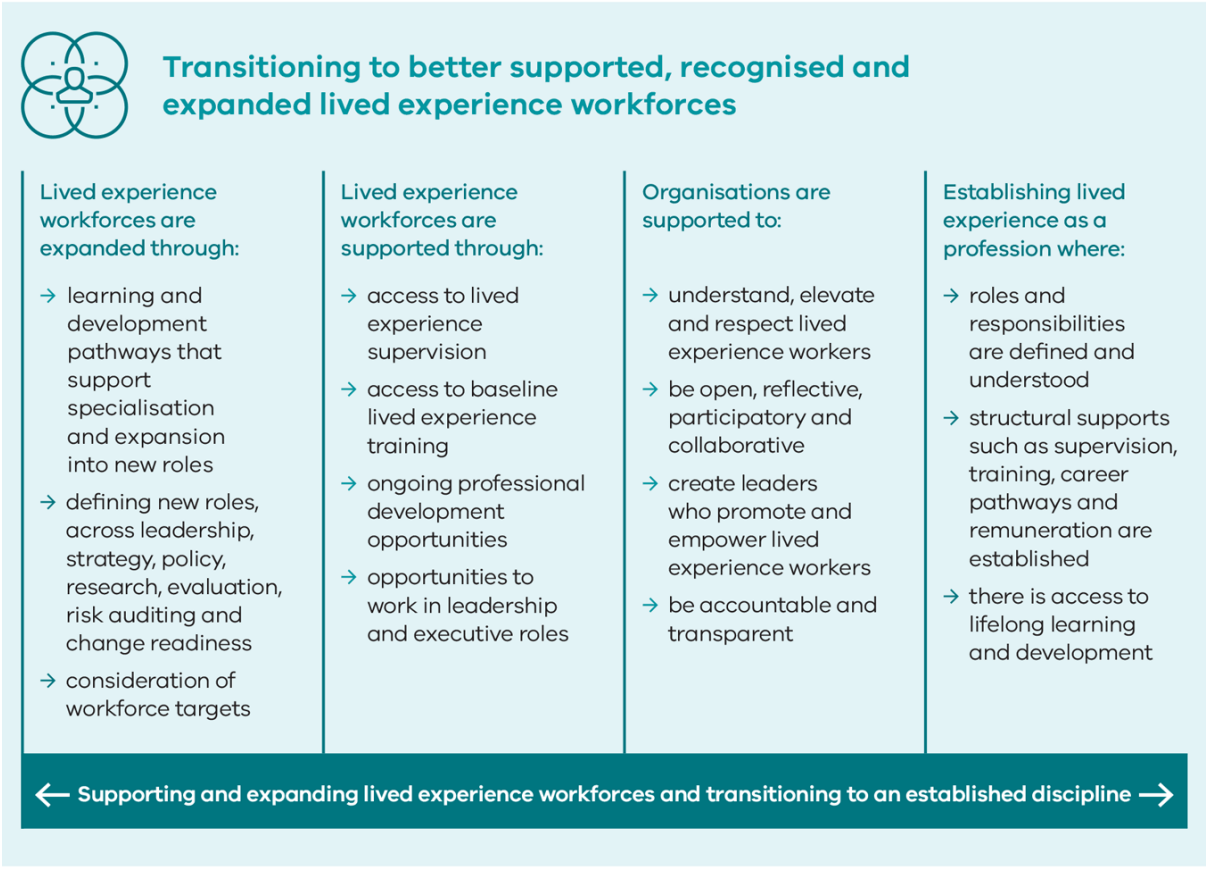
The completion in 2021 of Action 29 of the Fifth National Mental Health and Suicide Prevention Plan, the Peer Workforce Development Guidelines, will be a valuable resource for the mental health sector and the peer workforce.

[32] Available on the Lived Experience Australia website: https://www.livedexperienceaustralia.com.au/research-peer-project

This project will help support the consumer and carer peer workforce through providing formalised guidance for governments, employers and the peer workforce about support structures required to sustain and grow the workforce. Although local and regional consumer and carer peer workforce frameworks exist, the development of national guidelines will ensure consistency across Australia. National guidelines will also be a step towards professionalisation of the peer workforce.

Implementation of Action 30 of the Fifth National Mental Health and Suicide Prevention Plan will also support ongoing workforce planning and development for the consumer and carer per workforce. Action 30 states that "Governments will monitor the growth of the national peer workforce through the development of national mental health peer workforce data including data collection and public reporting". These data will be valuable for analysing, among other things, consumer and carer peer workforce growth in numbers and location and type of employment.

The Interim Report of the Royal Commission into the Victorian Mental Health System has described a model for the transition to better supported, recognised and expanded lived experience workforces.[33] The NMHHCF supports this approach.



Source: Royal Commission into Victoria's Mental Health System, 2019, Interim Report (Page 510)

[33] Royal Commission into Victoria's Mental Health System Interim Report, November 2019

The training and education requirements for peer workers has been identified as an issue in the development of the National Mental Health Workforce Strategy. The most common training for peer workers involves completion of the Certificate IV in Peer Work.

Alternate programs are being introduced which may attract a wider range of peer workers and provide alternate career pathways. One example is the Certificate II in Community Services being offered in NSW.[34]

Another program to support peer worker employment is the Advancing Successful Peer Inclusion and Readiness for Employment (ASPIRE) Project which is being led by Consumers of Mental Health WA (CoMHWA), in partnership with 360 Health and Community (360), and in collaboration with a network of employers in the disability and health sectors.[35] The ASPIRE Project is a partnership program between people with psychosocial disability and employers which aims to:

- boost employable skills and employment outcomes for individuals with psychosocial disability
- create new employment pathways for consumer and carer peer workers
- drive inclusive practices by employers
- increase the confidence and motivation of employers to employ consumer and carer peer workers.

This project is being delivered until February 2023 and is funded by the Australian Government Department of Social Services.

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.[36]

NMHCCF Recommendations

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Commits to five years funding for the peer workforce professional association to ensure the consumer and carer peer workforce professional association is sustainable beyond its establishment

[34] https://www.mhcc.org.au/course/certificate-ii-in-community-services/

[35] Further information is available at: https://comhwa.org.au/programs/aspire

[36] 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

- Supports the development and delivery of education programs relating to the peer workforce be provided by consumer and carer peer workers led by the peer worker professional association, with engagement with States and Territories
- Supports the education programs being provided to health professionals and also offered through clinical professional associations, mental health and community services and private providers
- Implements the training programs described above at an earlier date than proposed
- Supports the implementation of the Peer Workforce Development Guidelines, Action 29 of the Fifth National Mental Health and Suicide Prevention Plan
- Supports the implementation of Action 30 of the Fifth National Mental Health and Suicide Prevention Plan.

6. Lived experience peak advocacy and advisory body

Productivity Commission's perspective

The Productivity Commission has continued to promote enhanced participation of consumers and carers in the design of government policies and programs that affect their lives. (p. 1113).

One opportunity for this enhanced participation is through the establishment of new, separate peak bodies for consumers and carers. Specifically, the Productivity Commission has recommended that:

> "The Australian Government should fund separate representative peak bodies to represent the views, at the national level, of people with mental illness, and of families and carers." (Action 22.4, p. 1113)

The Productivity Commission recommends the Australian Government facilitates a process through which Mental Health Australia establishes these separate peaks "that are able to represent the separate views of mental health consumers, and of carers and families, at the national level" (Action 22.4, p.1113).

The final report also notes the Australian Government should "provide sufficient funding to cover the development, establishment and ongoing functions of these peak bodies" (p.1113). Another sub-action (with a 'start later' timeline) states that Mental Health Australia "should create formal mechanisms to bring the new peak bodies together regularly to progress issues of mutual interest and develop common policy positions and advice" (p.1113)

NMHCCF response

The NMHCCF supports the establishment of consumer and carer peak bodies.

The Forum also continues to support a combined consumer and carer voice. The development of formal mechanisms to bring together the lived experience voices should not be undertaken later in the implementation of this recommendation (p. 1113). The opportunity for shared understanding, discussion and debate on the intersectionality of issues and co-design opportunities will be missed if the combined voice is not established at an early time in the implementation of this Action.

Further, the NMHCCF supports the development of another body – a combined (consumer, carer and family) lived experience voice - rather than just a formal mechanism as recommended above, which would provide access to a legitimate and considered viewpoint representing the needs of the diversity of our population and those often under-represented from both a consumer, carer and family perspective.

The NMHCCF could continue in this role while another body is being developed, noting that the NMHCCF has, since its establishment by Health Ministers in 2002, been a combined national voice for mental health consumers and carers. NMHCCF members represent mental health consumers and carers from each jurisdiction and many organisations. 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 on many national bodies, such as government committees and advisory groups, professional bodies and other consultative forums and events.[37]

The NMHCCF received funding from the Mental Health Principal Committee in 2019 to lead a process to co-design a new, strong national mental health lived experience voice suited to today's environment and requirements. The outputs from this project area available on the NMHCCF website.[38]

The PC Report recommends that the establishment of the two peak bodies be led by Mental Health Australia. The NMHCCF does not have a view on which organisation should lead the establishment of the peak bodies but has identified specific issues to be considered by the lead organisation:

- the remit of the two new bodies is in representing mental health consumers and mental health carers and families. The NMHCCF would not support the role being subsumed as a subset of a broader consumer and carer peak bodies

- governance structures need to be developed and led by mental health consumers, carers and families

- co-production and co-design approaches must be used when developing the two new peak bodies and any other structures that will support them

- in utilising the work undertaken previously by Mental Health Australia, and others, for the development of a Consumer Reference Group (as recommended by the Productivity Commission) the needs of mental health carers and families are specifically identified and not just adapted from work that was developed for mental health consumers

- the progress of time and its impact on the outcomes on the work undertaken previously by Mental Health Australia, and others, needs to be considered when developing the plans for the establishment of the two peak bodies

- individuals who are both consumers and carers should be able to be a member of both peak bodies

[37] Details of the work of the Forum in 2019/20 are available at: https://nmhccf.org.au/sites/default/files/docs/nmhccf_annual_summary_report_2019-20_-sept2020.pdf

[38] Available at: https://nmhccf.org.au/publication/nmhccf-combined-lived-experience-voice-workshops-final-output-report-august-2020

- a formal mechanism is established for the national peak bodies to link with peak bodies in states and territories.

The Productivity Commission has also recommended that "the National Mental Health Commission should report annually on the state of systemic advocacy in mental health in Australia at a State, Territory and national level". (p.1113)

The NMHCCF supports this recommendation while asking that any report captures the perspective of people with lived experience and not just the perspectives of NGOs or other organisations that represent consumers, carers and families.

NMHCCF Recommendations

In progressing the recommendations from the PC Report the NMHCCF requests that the Australian Government:

- Consider the establishment of a combined lived experience voice in additional to the consumer and carer peak bodies recommended
- Ensure the mechanism for the combined lived experience voice is established early in the implementation of the recommendation
- Ensure the remit of the two new bodies is in representing mental health consumers and mental health carers and families and not subsumed into more general consumer and carer peak bodies
- Ensures that the consumer and carer peak bodies are established using co-production and co-design approaches
- Ensures that the needs of mental health carers and families are specifically identified and not just adapted from work that was developed for mental health consumers
- Ensures that the annual report on the state of systemic advocacy in mental health in Australia at a State, Territory and national level captures the perspective of people with lived experience and not just the perspectives of NGOs or other organisations that represent consumers, carers and families
- Ensures that the combined voice has representation from all jurisdictions and diverse population groups such as Aboriginal and Torres Strait Islanders and Culturally and Linguistically Diverse and reach into the communities they represent.