



Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

Supplementary Submission

To the

Productivity Commission Inquiry into Mental Health

Dated 22 July 2019

Executive Summary

This is a Supplementary Submission to the Productivity Commission from our original Submission Number 49.

We wish to address specifically the issue of engagement at all levels, of people with mental illness (lived experience) and their families and carers at the individual, service, state and national level.

We have made some further recommendations in this regard but the essence of true partnerships with consumers and carers is to listen and come to shared understanding of how best to go forward together; that is, to listen to the views, opinions, perspectives and experiences that value add to all areas of mental health.

A great deal is talked about partnerships with consumers and carers. Co-design¹ is also a newer introduction concept, now used within mental health, but true co-design is a concept that is not being achieved in most places.

We have set out some of the context of what we understand to be generally the case, noting that some services, organisations and jurisdictions, including nationally, do well with consumer and carer engagement. We have also articulated what we believe should be done to make a real and lasting difference.

Many mental health consumers and carers feel that their presence and 'inclusion' is more a tick box exercise rather than service providers and policy makers genuinely seeking their views and perspectives.

If we look at the concept of 'patient centred care' something articulated consistently these days and one the Network believes in, surely it is crucial to design services to meet the needs of consumers, rather than designing services first and expecting consumers to fit the services.

What is the value of genuine consumer and carer engagement and inclusion?

We believe that when we are meaningfully involved in designing services right from the start, we can provide perspectives which detail experiences, provide solutions to gaps or barriers, resulting in scarce dollars being expended in the right place, at the right time, for the right people. The value of this approach in the funding sense, is a more efficient and potentially less costly service or program that better meets the needs of consumers and carers. An example of this is the *Partners In Recovery* program (PiR). See Case Study one on page 5.

¹ Co-production Putting principles into practice in mental health contexts: 2018, https://recoverylibrary.unimelb.edu.au/data/assets/pdf_file/0010/2659969/Coproduction_putting_principles-into-practice.pdf

Commissioning Mental Health Services, A Practical Guide to Co Design: PHN Central and East Sydney 2016 <https://www.cesphn.org.au/preview/our-region/1270-commissioning-mental-health-services-a-practical-guide-to-co-design-august-2016/file>

Co-design in Mental Health Policy, Mental Health Australia, July 2017 https://mhaustralia.org/sites/default/files/docs/co-design_in_mental_health_policy.pdf

Co-design and Co-production, National Mental Health Consumer & Carer Forum, 2017 https://nmhccf.org.au/sites/default/files/docs/nmhccf_-_co-design_and_co-production_ab_-_final_-_october_2017_0.pdf

Co-designing a better mental health system, NSW Mental Health Commission, 2018 <https://nswmentalhealthcommission.com.au/news/commission-news/putting-lived-experience-at-the-heart-of-our-mental-health-system>

Perhaps a hypothetical discussion in terms of cultural change and attitudes around engaging and involving consumers and carers might be the founding philosophy of medicine and particularly psychiatry itself. Within the mental health system, consumers who are deemed at risk to themselves or others can be involuntarily admitted under mental health legislation and can be required to under-go treatment that they may not want to have. This is by no means being critical of psychiatrists or any other clinicians, rather seeking to understand why things haven't changed that much over a long time. If the environment of medical and specialist schools, training, required adherence to legislation and clinical practice determine the approach of 'doing to rather than doing with' or a differential in power, might it also result in these experiences and learnings being carried into consumer and carer engagement as an unconscious learned way of doing things rather than 'please tell us what the solutions are'

When things are planned for you as an individual without any interactions with you, and which may not meet your needs or requirements, the human response is usually one of non-acceptance, an unwillingness to compromise and lacking the legitimacy of self-determination.

The challenge for all stakeholders including consumers and carers now and into the future is a focus on 'this is a new way of doing business'. What is required we believe is to work toward compromises and promote and enable changes in culture and attitudes.

What is needed is to engage consumers and carers in a meaningful and significant or genuine partnership (co-design) approach founded on mutual respect right at the very beginning, where all parties are equal, have expertise in different areas, and bring real value and shared knowledge to the table.

Our Recommendations appear on pages 9 and 10.

Introduction

Much has been written about consumer and carer engagement and this has been articulated in many policies, protocols, publications and plans since the beginning of the National Mental Health Strategy of 1992. The Strategy has been reaffirmed by the health ministers a number of times since that date. In 1998 the *Second Mental Health Plan* was developed, and in 2003 the *National Mental Health Plan 2003-2008* was endorsed with the *Fourth National Mental Health Plan* released in November 2009. And now the 5th National Mental Health and Suicide Prevention Plan. The message across each and all of these plans has been for genuine consumer and carer engagement as a core principle.

A further requirement for consumer and carer engagement has been articulated within the National Standards for Mental Health Services (NSMHS), and the National Safety and Quality in Health Care Standards editions 1 and 2 (NSQHCS) with a specific standard: Standard two: Partnering with Consumers, focussing and guiding services and organisations on this issue.

However, despite the articulation of the requirements for consumer and carer engagement within these national initiatives, there is a great deal of concern about the understanding and true nature of engagement and whether this is genuine, real, tokenistic or simply a process to tick boxes rather than genuinely seeking the perspectives and experiences of consumers and carers.

There are four levels of engagement namely:

- 1) Individual level
- 2) Service level
- 3) State level
- 4) National level

We will describe each of these levels hereunder.

Individual level engagement

The Network is of the view that this is not being done consistently, and that people are not always engaged in decisions to the extent that perhaps they should be about their care, treatment, supports etc. Even at this level, there is a lack of consistency about the development of care plans, management plans, discharge plans etc. There is still a view that many consumers are not included in discussion about their plan and don't receive a copy. In the main families and carers are rarely engaged or involved in the development of these plans yet these are requirements under the NSQHCS. Discharge planning is another area that requires vast improvement, with consumers and family members often unaware and not included in planning for their discharge.

This is an area that the Network believes is critical to the ongoing management of people's lives and the support of families and carers in the recovery processes. People do not live solely in isolation; they are part of communities where reciprocity and naturally occurring supports are as valuable to recovery as clinical care.

Service level engagement

The public mental health services and community managed organisations (CMO's) do reasonably well in engaging consumers in the development of brochures, and low-level initiatives. In the public sector local engagement is often dependent on the culture and attitude of the staff, many are inclusive of consumers and carers, but this can vary considerably across services and areas. Generally CMO's are much more inclusive of consumers and family members/carers, with input sought on a range of issues. Many have structures and mechanisms for engagement which are meaningful.

This engagement is not to be confused with the peer workforce where peer workers (those in a defined and paid lived experience role) provide key and unique perspectives and services.

At this level the consumers are more like representatives (rather than advocates or employed peer workers) in the true sense of consumer and carer views and perspectives in the design or evaluation of programs etc provided within these settings. There is also a tendency at this level of mental health services to privilege the views of a very small number of consumers (or only one consumer who they view as aligned with their mandate), and consider the job of consultation achieved through often quite limited and potentially non-representative engagement and participation of the wider population they serve. This can engender mistrust and fatalism that little will change, and the view of important subgroups of consumers can be overlooked altogether.

The private hospital sector broadly has difficulties in engaging consumers and carers for a number of reasons. Some private hospitals strive for meaningful engagement of consumers and carers; others are less willing, noting the commercial environment in which they operate, legal ramifications, employment and other risks. Some corporate hospital providers have one central and national consumer and carer entity which speaks for and on behalf of each individual hospital.

The Network has increased funding to offer workshops in all major cities over the next 3 years where education and training on consumer engagement and partnership will be provided including the provision of presentations to staff and management.

State level engagement

This is where the advocacy, experience and perspectives of people with a lived experience of mental illness and their families and carers should be engaged to provide their unique expertise across all

areas, planning, design, delivery and evaluation of programs and services delivered within the respective jurisdiction.

It is in this area that we believe a great deal more could be achieved by genuinely seeking and including the expertise of consumers and carers. Having one representative on a committee/working group or similar is not satisfactory given the other people at the decision making table are usually clinicians, policy officers, departmental staff, management etc. This environment can be overwhelming for the strongest of representatives with only one voice trying to bring the unique consumer and carer perspective for consideration. This is not what is considered to be true co-design and often maintains the status quo, which is largely crisis driven mental health systems delivering programs and services that find it difficult to fit or benefit the needs of consumers or family members. Consumer and carer representatives find this probably the most challenging of all, as it is often felt that their input is tokenistic in the main, with their representation being merely a tick box, rather than true engagement.

Some jurisdictions have organisations that advise on various aspects i.e. Tandem, and Victorian Mental Illness Awareness Council Inc. in Victoria, Being in NSW, Flourish in Tasmania, HelpingMinds and Consumers of Mental Health WA. Whilst these organisations can provide representatives, we are concerned that this does not equate to the direct engagement in service design, delivery and evaluation that is necessary to drive substantial and meaningful reform.

Where there is no dedicated (representative) organisation, establishing a lived experience advisory group would be a way forward. This would be a conduit for advice, and a mechanism leading to the governance levels reporting directly to the mental health leadership, mental health executive or governing board such as the LHNs.

These representatives require training, support and other aspects of their positional requirements and these can and are often undertaken by the organisations above. However in the jurisdictions where there are no dedicated or engaged consumer or carer advocacy organisations, many representatives do it tough. Capacity building is a key to quality representation.

The Network has developed a number of resources to better support these representatives which are free and can be accessed on: <http://pmhccn.com.au/Resources/TrainingResources.aspx>

We have detailed hereunder three examples 'case studies' of what has been a great result of engagement and inclusion of consumer and carer perspectives and experiences, both highly successful programs offering cost effective services to best meet needs.

CASE STUDY ONE – National Level Engagement

Partners in Recovery initiative

This program/service was designed over time, with all stakeholders being equal around the table. The Department of Health drew together a group of various representatives to determine a solution to those consumers who were the more serious and complex group, who cost the mental health system large amounts because of multiple inpatient admissions, as well as costs to police, ambulance, justice systems. The question was what could be determined to better meet the needs of this group.

The group included a consumer, a carer, departmental staff, clinicians, representatives from housing, education, justice, police, emergency departments, community sector etc in a number of round table discussions. The PiR was a highly successful service valued by consumers and carers especially in that it offered a true partnership approach, funding to organisations as fund holders, flexible funding for the consumer to wrap the necessary individual services around them to support and assist in their recovery and inclusion and support to carers.

The main drivers and architects of this initiative were the consumer and carer representatives who articulated the needs from their own perspectives and experiences and were willing to negotiate the best outcomes based on a collaborative approach. As mentioned this service was highly successful in that it met the needs of both consumers and carers, and in many ways alleviated the burden of caring for the families. Here is a great example of crucial consumer/carers engagement.

<https://humepir.org.au/wp-content/uploads/2015/06/the-success-of-partners-in-recovery.pdf> and also the testimony of how PiR was so successful. <https://www.youtube.com/watch?v=-NUthR0Fv7w>

Similarly to PiR, another gold standard in consumer and carer engagement is the new South Australian statewide service for people affected by borderline personality disorder.

CASE STUDY TWO – State Level Engagement

BPD Co – SA statewide service for borderline personality disorder.

The Borderline Personality Disorder Collaborative (BPD Co)

Consumers and carers were engaged in all aspects of the new service. These were amongst other things:

- 1) Political lobbying by consumers, carers and clinicians successful obtained \$13 million funding over four years for the establishment of the service;*
- 2) Design of the premises including colour scheme, graphics and name;*
- 3) Representation on all steering groups to inform the shaping of the service model;*
- 4) Representation on the 12 month Steering Committee which oversaw all the development of the service;*
- 5) Representation on recruitment panels for all staff including the clinical lead;*
- 6) A representative worked with the clinical lead to develop the model of care in a joint capacity;*
- 7) Representation on the Advisory Committee going forward;*
- 8) Provided personal presentations on their perspectives at the launch of the service by the Minister for Health and Wellbeing; and*
- 9) A specifically designated room titled the 'Janne McMahon Room' with a plaque in acknowledgement of services provided*

It is this service and the true engagement of consumers and carers as equal partners in all aspects of the establishment of this service which is impressive. It is the gold standard if you like on how things should and could be done.

The executive genuinely sought the perspectives of consumers and carers right from the start not because they had to, but because it was the view that this was instrumental in guiding where funding should go and what requirements there were to meet the needs of consumers and families and carers.

There is much excitement and a real sense of ownership of the service by consumers, carers, clinicians, SA Health and the Minister.

We have included within this Submission a case study which we believe is unique in many ways from a learned professional college, **The Royal Australian and New Zealand College of Psychiatrists (RANZCP)** We believe this is exemplary and provides a sound basis of what true consumer and carer engagement and co-design represents.

This appears on the following page:

CASE STUDY THREE – Organisational Engagement

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) established in 1996 a Community Collaboration Committee (CCC) which has fulfilled a crucial and important role in communicating the views and experiences of the community to the psychiatric profession. Through a true partnership model it has enabled community members and specialists to work together to meet challenges to the mental health system and to promote best practice care. In addition to the CCC community members also sit on a wide range of RANZCP committees including some faculties and sections within the RANZCP and most importantly the Members Advisory Committee which sits under the Board in terms of governance.

The CCC is co-chaired by a carer and a psychiatrist, showing confidence in the engagement of consumers and carers within the RANZCP. Personal experiences underpin the work and deliberations of the Committee. The CCC has consumers, carers and psychiatrists as members, and both together use their experience and different perspectives as a means for improving the care received at each point in our mental health system.

The diverse experience and expertise of the members of the CCC is evidenced by the work they have undertaken thus far, and the work planned for the future. The Committee have ownership of a number of position statements on topical issues such as *'acknowledging and learning from past mental health practices'*, *'supporting carers in the mental health system'*, *'recovery and the role of the psychiatrist'* as well as a number of other projects on topics allied to the participatory model of care.

National Level engagement

It is the opinion of the Network that people are well skilled in representation and advocacy at this level. There are currently three main sources for seeking representation, these are:

- 1) The Private Mental Health Consumer Carer Network (Australia) Ltd
<http://pmhccn.com.au/>
- 2) The National Mental Health Consumer & Carer Forum
<https://nmhccf.org.au/>
- 3) The National Register – administered by Mental Health Australia
<https://mhaustralia.org/report/national-register-mental-health-consumers-and-carers>

All three organisations are sought to provide consumer and carer representation to the Australian Government Department of Health, Department of Social Services, National Disability Insurance Agency, National Mental Health Commission. The NMHC has a number of documents to reference in the consumer and carer engagement space².

² NMHC, Consumer and Carer Engagement Project, 2018

<https://www.mentalhealthcommission.gov.au/media/253244/Sit%20beside%20me,%20not%20above%20me%20-%20Supporting%20safe%20and%20effective%20engagement%20a....pdf>

NMHC, Engage and Participate in Mental Health, 2018

https://www.mentalhealthcommission.gov.au/media/237285/NMH18-3769_Engage_Participate_Report_ACC_2.pdf

NMHC Paid Participation Policy, 2019

<https://www.mentalhealthcommission.gov.au/media/255735/Paid%20Participation%20Policy%20revised%20March%202019.pdf>

NMHC Work Plan 2015-16 Pg 2 of 14

<https://www.mentalhealthcommission.gov.au/media/125332/Workplan%202015-16.pdf>

NMHC Contributing Lives Review, 2014 and other years

<https://www.mentalhealthcommission.gov.au/our-reports/our-national-report-cards/2014-contributing-lives-review.aspx>

It is the opinion of the Network that these entities understand the nature of consumer and carer engagement. It is our opinion that our representatives' voices are heard, sought and we feel equal members of any working groups, committees, reference groups etc.

It is our opinion that in the most part these entities 'get it'. However, when it comes to large scale funding of initiatives, we are concerned that this could be better prioritised. An example is the funding for Headspace. It has been reported to us that should the young person show signs of persistent or acute mental illness; their care is often transferred to the public mental health child and adolescent or youth services where funding and staffing are limited with these services having difficulty meeting demand. Young people are often forced to wait long periods if a transfer to the public service is deemed necessary, leaving the client feeling abandoned, and without hope for the future.

Primary Health Networks are also an area where consumer and carer engagement is evolving. Some do it well for example the Brisbane North PHN and South Eastern NSW PHN; others could do it better. This should include consumer and carer input into tender reviews for service commissioning, evaluation of services etc could be embraced. We are hopeful that the engagement will continue to be rolled out in a true partnership model. Some accountability to ensure community and consumer and carer engagement is ongoing would be of value.

What should we do to make a difference?

Given the articulation of consumer and carer engagement since 1992, we are still having the same discussions 27 years later. It leaves many consumers and carers questioning the genuineness of engagement. What we have seen in the HIV and STI areas, for example, makes mental health pale into insignificance. Further we question how services and organisations currently meet the accreditation standards established by NSQHS.

It is therefore seen by consumers and carers that their true engagement in the mental health system is tokenistic in the main. The question is: What would make a difference? We recommend the following:

- 1) At the most basic level is listening.
- 2) Secondly genuinely sought views, input and perspectives of consumers and carers is required. These include choice and control of our own care or that of someone we are supporting. It also includes partnering with us in all things, i.e. being spoken with rather than spoken to.
- 3) Rights, all of those articulated within the National Mental Health Strategy, plans, accreditation requirements etc which require the genuine engagement of consumers and carers into service planning, delivery and evaluation. The right to ask questions and receive informed responses.
- 4) Applying and implementing co-design principles
- 5) Communication that is inclusive (not exclusionary) is a key issue between consumers and carers and the services designed to care for them.
- 6) Capacity building. Our Network has designed the following 5 modules from *The Kit, the Advocacy We Choose to Do*, a publication of the first national mental health strategy.

We have modules for:

- Looking after yourself
- Keeping the Enthusiasm Going
- Briefing and Debriefing
- Self reflection and self evaluation

- Advocacy and the Organisation

We also have modules for service staff which attract continuing professional development (CPD) points from the RANZCP and Australian College of Mental Health Nursing including:

- Module 1 Consumer and Carer Involvement
- Module 2 Continuity of Care
- Module 3 Communication
- Module 4 Cooperation (Roles & Responsibilities)
- Module 5 Collaboration

Here is the link: <http://pmhccn.com.au/Resources/OnlineTraining.aspx>

System wide governance level

The key components are:

- Genuine partnerships
- Implementing the concepts and requirements of Standard two: Partnering with Consumers NSQHC. There is often a lack of adherence to the meaningful and genuine engagement of consumers and carers across the different domains.
- Appointment of consumers and carers at the governance level i.e. on boards, Mental Health Leadership, Mental Health Executive etc.
- Cultural change in terms of:
 - Recognition that this is a new way of doing business
 - Accepting this is a whole new paradigm
 - Potential to enhance recovery-focussed practices and improved outcomes
 - Engaging consumers and carers right from the start whenever an issue or need is identified. Partnering at the initial stage would ensure the needs of consumers are genuinely met resulting in services planned and delivered according to these needs. This would ensure the tight dollars are spent in the most effective way and bring about better value for money.
 - Utilising consumers and carer input at the state levels including into policy, guideline development, frameworks etc is crucial.

Recommendations

This Submission covers the following recommendations

We have made a number of Recommendations which we would appreciate being considered by the Productivity Commission as a matter of urgency. A real need for cultural change is needed now. In essence these are all co-design principles:

Recruitment

- **Recommendation 1:**
Appoint consumers and carers on key decision making entities such as Boards, Mental Health Executive, Mental Health Leadership, Australian Government led initiatives such as strategic planning, funding applications etc.
- **Recommendation 2:**

Adhere to the transparent process for recruitment and selection of consumers and carers.

National Safety and Quality Health Care Standards

➤ **Recommendation 3:**

Introduce concepts of Standard two: Partnering with Consumers within processes at the state level as the model clearly articulates the requirements for true partnership. It could be used in a much greater capacity that just at a service level and adds accountability and evidence in terms of actions.

➤ **Recommendation 4.**

Ensure increased auditing at the service level and state level of the compliance of care plans, management plans and discharge plans.

Advisory Entity

➤ **Recommendation 5:**

Where there is no direct input into key jurisdictional committees, establish a Lived Experience Advisory Group with direct reporting to Mental Health Leadership and/or Mental Health Executive.

Capacity Building

➤ **Recommendation: 6:**

Uptake of the Network's training modules to consumers, carers and clinical staff which are free and delivered online.

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