

Promoting lived experience in mental health



A summary of discussion and outcomes from a forum held on 29 July 2016.

Introduction

Under the *Queensland Mental Health, Drug and Alcohol Strategic Plan 2014–2019* (Strategic Plan) the Queensland Mental Health Commission is committing to several initiatives to Shared Commitment to Action 1: Engagement and leadership priorities for individuals, families and carers. This commitment seeks to improve inclusion, meaningful participation and outcomes by drawing on the diversity of the experience and wisdom of people with a lived experience of mental health difficulties and problematic substance use, their families, carers and support persons.

On 29 July 2016 the Commission hosted a forum with government and non-government representatives and people with a lived experience of mental illness to discuss participation of people with a lived experience in the mental health sector.

Details of the *Promoting Live Experience in Mental Health Forum* can be found at Attachment 1.

As part of this work the Commission contracted Dr Louise Byrne to assist it to enhance community and industry support for consumer participation and paid consumer roles and improve mental health consumer contribution to system change in Queensland. Her contribution included preparing a paper to inform the forum.

The Commission notes that participation at this forum was limited to those individuals from South East Queensland. There will be opportunities for other organisations and individuals to participate in this ongoing discussion.

This paper summarises the discussion that was had at the forum on the following four key themes:

- opportunities for lived experience participation in the mental health system
- major barriers to lived experience participation from the perspective of different stakeholders

- potential options for addressing those barriers and who would be best placed to lead them
- identifying which options are most needed and most likely to be viable and effective.

The rest of this report provides a summary of the discussion, comments and suggestions that were raised across the activities that occurred at the forum. No attribution is made to individual participants and the information is presented in an aggregated manner.

Session one

Promoting lived experience discussion paper

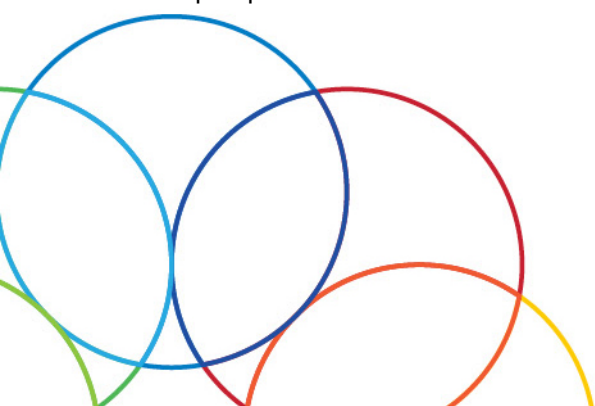
This session commenced with a general discussion of the term 'lived experience'. It quickly became apparent that this is a contested space and a discussion about the word 'expert' and 'expertise' ensued. Ultimately, the issue of language and its potential impact was recognised but there is general agreement of the value in ensuring that people who have experience of mental health are given the opportunity to have a 'voice'. (For ease of purpose the term 'lived experience' will be used throughout this report).

An issue about the discussion paper excluding 'suicide' was raised. It became apparent that this had occurred because while suicide is often underpinned by mental illness there is a perception that some people with a lived experience of suicide want a 'space' separate from the broader 'space' of mental health.

The participants sought clarification of who the intended audience of the discussion paper was. Dr Byrne's response was 'hirers and firers'. There was a discussion about whether this was just about 'peer support workers' or support for anyone with mental health problems or illnesses. It was perceived that the document could be used as a 'sales pitch'.

It was agreed that a number of additional references would be included.

A discussion was had in relation to the section in the discussion paper about Intentional Peer Support (IPS) training. It was noted that while it is identified by Queensland Health as a 'requirement' for peer workers in community care units this is not necessarily the case.



Other courses were noted and it was generally recognised that no one course is universally endorsed. Participants discussed the need for competency and what employers actually wanted from positions such as peer support workers. There was recognition that lived experience is required across a range of positions (e.g. trainers, managers) and that starting as a lived experience position often enables people with mental health issues or illness to move into other positions which may or may not require a lived experience.

The issue of reasonable adjustment, that is changes to a job, which can be made to enable a worker to perform their duties more effectively in the workplace, was raised as well as the issue of governance and supervising people in the work place who experience a mental health issue or illness. It was identified that in any sector there needs to be appropriate management support.

Participants also raised issues of the lived experience of people from culturally and linguistically diverse backgrounds, Aboriginal people and Torres Strait Islanders and people from rural and remote areas.

Participants were provided an opportunity to write some of their ideas and issues down for the discussion paper. These were passed on in full to Dr Byrne and are summarised below:

- History of the lived experience movement needs to be acknowledged.
- Need to examine power differences and history of participation.
- The 'why' of lived experience and contributing competency could be stronger.
- What lived experience brings to an organisation that is functionally different from non-lived experience needs to be clearly defined.
- Consider S.U.R.E – Service User Research Evaluation.
- Lived experience consultation roles.
- Lived experience workforce should not be promoted as a 'low cost' workforce.
- Lived experience leadership development could be strengthened.
- Consider including reference to both the National Safety and Quality Health Service Standards and Standards for Mental Health Services as both part of compulsory accreditation and both require consumer participation or engagement.

Session two

Opportunities created by lived experience in the mental health system

In this session Michelle Feenan requested participants at their tables to list the best opportunities that lived experience provides for the mental health system. The top opportunities are listed below in no particular order:

- Lived experience gives a 'massive' head start in relationship building.
- Shaping new organisational change opportunities by lived experience.
- Cultural reform through change management.
- Peer workers in emergency departments.
- All and any roles a person has a skill for.
- Improving perception of people through creative processes.

Why use 'live experience'?

Participants identified a number of reasons why lived experience was positive. These included that lived experience leadership and supervision could improve system design and change and enabled jointly developed services and delivery which could all lead to increases in the quality of care and services provided to people living with mental illness. Participants also highlighted how embracing lived experience can increase the acceptance of and reduce the stigma experienced by people with mental illness. The engagement of people from culturally and linguistically diverse backgrounds with a lived experience can also assist services to be more responsive.

Importantly new opportunities are still emerging from using people's lived experience; the process will be iterative and will require feedback loops as opportunities become embedded in the sector.

Lived experience roles

Participants identified the importance of having a lived experience across a diversity of roles and levels within the mental health system. This extended beyond peer support roles into managerial, decision making, and system influencing positions. It did also include a call for additional peer support roles in particular areas of the health system (e.g. acute crisis units, high dependency units) as well as those sectors/agencies where there is a regular interaction with people living with a mental illness (e.g. Centrelink, housing services, employment agencies). Some participants suggested

that publicly funded programs (such as Personal Helpers and Mentors) should be mandated to employ people who have a lived experience. Participants also suggested that there should be peer run step-up and step-down facilities.

Underpinning the lived experience workforce was a requirement to support access to appropriate and accredited training such as scholarships for people with lived experience to access Certificate 4 in Mental Health Peer Work. Some participants saw people living with mental health issues and illness as potentially an untapped workforce.

Why a lived experience workforce?

Participants suggested that having a workforce with lived experience, especially in mental health and associated social services supports the likelihood of a more compassionate workforce and a workforce that is able to develop better rapport with its consumers.

Beyond the mental health workforce

Participants viewed that people with a 'lived experience' had a role beyond the direct delivery of mental health workforce and in particular this related to the concept of education. Education was taken from the perspective of teaching mental health professionals and leading research into mental health. Participants also viewed people with a lived experience having a role to provide education to the general community about issues of mental health and the focus on supporting people with mental illnesses on a journey of recovery rather than a trajectory of permanent disability. Providing voice to people with a lived experience through community education programs was also seen as a way to reduce stigma associated with having a mental health issue or illness.

Session three

Barriers to lived experience in the mental health system from different perspectives

In this session participants received the three following scenarios and were asked to describe the barriers associated with them from the perspective of different groups of stakeholders such as consumers, family/carers, co-workers, lived experience workers, managers.

Scenario 1: Employment

Linda is 45 years old. She is a single woman and a mother to three children in their early 20s. Linda has a significant history of mental illness since her early teenage years with a diagnosis of bipolar disorder made in her early 30s. Linda has had numerous hospital admissions and a long history with community mental health services and non-government organisations.

Linda's symptoms have been well managed for the past four years and she reports that part of her 'stability' has been achieved with the assistance of peer support workers and the recovery oriented mental health practice that they supported.

Now that Linda's children are self-sufficient Linda would like to be more involved in the community through work and in particular thinks that she has something to offer others who are experiencing mental illness. Linda's education and employment experiences have been severely impacted by her mental health.

Scenario 2: Hospital and Health Service

A mental health service within a Hospital and Health Service has just received approval and funding to employ two permanent peer support workers. These are the first peer support workers this mental health service will have ever had. The decision to seek approval and funding for these peer support workers was determined through consultation with consumers, carers, staff and other non-government organisations in the region. If the peer support workers are successful then there may be an opportunity for additional positions to be created.

The Hospital and Health Service and consequently the mental health service covers a regional and remote population with some key regional towns. The service has a high proportion of Aboriginal and Torres Strait Islander clients.

A reference group has been established which includes staff (medical, nursing, allied health and Aboriginal and Torres Strait Islander Health Workers), two consumers, one carer and one representative from a local mental health non-government organisation. The group will discuss and articulate more definitively the role and expectation of the peer support worker positions, the key selection criteria for choosing the most appropriate candidates and the support framework for the successful job applicants. Other issues that are likely to be discussed include socialising these positions into the mental health service, the service recipients and other stakeholders in the region.

Scenario 3: Non-government organisation

A mental health non-government organisation has a relatively large workforce of peer support workers and prides itself on being a leader in regards to peer support workers. Lately, however, there has been tension between those peer support workers who have undertaken formal qualifications in peer support work and those who have not.

The non-government organisation has also noticed that clients are preferring some peer support workers over others, however, they note that there is no consistency in terms of the preferred support workers having a formal qualification or not.

The different barriers put forward by participants are listed below:

- Often people who have experienced or a living with mental illness may not be aware of the full range of employment opportunities that may be available to them (importantly people should not be boxed into one type of employment because of their lived experience).
- People with lived experience may still feel stigmatised; may feel self-conscious about their mental health issues/illness.
- There is a need for bridging support which could include but is not necessarily limited to:
 - education and training
 - work experience
 - work readiness
 - confidence building
 - framing skill set.
- Insufficient pre-employment support and a lack of comprehension of what people with lived experience can contribute.
- Lack of qualifications is a barrier to employment. For organisations it may represent a cost associated with needing to train a person with lived experience who does not have any specific qualifications.
- Lived experience of mental illness is necessary but not sufficient to ensure someone is a good peer work or even suitable to be a peer worker.
- There is lack of agreement in relation to the role expectation of people with lived experience.
- There is a desire to fit someone into a role rather than accepting diversity and what individuals can contribute.

- Volunteering with appropriate training has occurred but services have diminished the value of the lived experience.
- There is a need to re-engineer work to appropriately support the accommodation of people with a lived experience.
- Concerns regarding relapse and what 'stability looks like'.
- Concerns that lived experience does not make a person an expert on all consumer experiences.
- Anxiety and concern from other staff who do not have a lived experience (need for investment in supporting non-lived experience staff).
- Risk adversity in workplaces prevents cultural change. Organisations need to embed, explore and tolerate the perceived risk in order to bring about change. Organisations' expectations around reasonable adjustment.

Session four***Ideas to support change***

In this session participants at their tables were asked to come up with ideas to support lived experience within the workplace. Other participants then had the opportunity to rate the idea in terms of their agreement (strong agreement, agreement, neutral, disagreement, strong disagreement, confusion). Then participants had the ability to make a statement about the idea's strength and opportunities and concerns and weaknesses.

The following ideas were presented. They are not listed here in any particular order.

Idea: Safety circle for workers

The idea behind this is that there is a real or virtual space for workers to connect if you are experiencing a struggle of any type (not necessarily just a mental health issue).

Thirteen participants identified strong agreement or agreement with this idea. One expressed neutrality and one expressed disagreement. The following strengths and opportunities were identified:

- supportive workplace particularly for organisation where workers are exposed to vicarious trauma
- CAPS – on Facebook already exists and is excellent for support from others
- Uniting Care Safe Space Project.

In relation to concerns and weaknesses the following issues were raised:

- where will funding come from?
- who is to say that all people have the same attitudes and approach to practice?
- prefer learning circle rather than implied need for safety.

Idea: Organisations need to embrace, explore and tolerate perceived risk to bring about culture change

Sixteen participants expressed strong agreement or agreement for this idea. Two expressed neutrality to this idea. The following strengths and opportunities were identified:

- need a practical risk strategy that not only identifies risks but also provides a means to reduce it
- co-production of safety assessment
- can we experiment within existing culture – it will change culture by doing this.

One participant asked is it the culture that is stopping us or is it an excuse we tell ourselves to prevent the change from happening.

Idea: Lived experience leadership innovation hub

The following statement was presented with this idea *“we commit to continuing the conversation that fostering ‘self-leadership’ to contribute to organisation change and development of ideas. This will happen through an invitation to people who want to experiment with new/provocative ideas to explore change using experiential learning”.*

Twelve participants expressed strong agreement or agreement with this idea. One participant expressed confusion.

Under strengths and opportunities there was mention of the International Lived Experience Leadership Academy (Yale/Anthony Stratford/Larry Davidson Proposal). Under concerns and weaknesses participants wrote:

- may require guidance to develop
- professionals may try to lead this – lived experience must lead
- need space for action as well as ideas
- who will fund this?

Idea: Staff education/training

This idea suggests the nurturing of new voices, raising empathy through stories/sharing experiences and targeting specific areas of influence.

Thirteen participants strongly agreed or agreed with this idea and one expressed confusion. Under strengths and opportunities the following statements were listed:

- learning through experience
- new voices = new blood = positive outcomes
- new voices cumulative knowledge
- internal leadership.

Under concerns and weaknesses the following statements were made:

- requires safe and constructive disclosure – concerns of inappropriate sharing
- who provides the education and what is its focus?
- Need commitment from executives.

Idea: Funding for people with lived experience to do a Certificate IV in Mental Health Peer Work

Seventeen participants strongly agreed or agreed with this idea. Four participants were neutral and one expressed disagreement. Under strengths and opportunities the following statements were made:

- speak to local mental health services (government and non-government) and get them to commit a small amount of funding ~ \$4000 is not a lot to a whole service
- a good place to start
- Brisbane North PHN peer participation project subsidised Cert IV through Spectrum Training
- standardise roles.

The following were statements made under concerns and weaknesses:

- focus on qualifications rather than value skills and relationship
- concern that services are demanding this qualification – may not be the ‘be all and end all’
- cost
- lived experience work is far broader than peer work.

Idea: Lived experience led wide scale recovery education for the general public

The concept behind this idea is that this would enable the general public to understand the shift in mental health thinking and service delivery and this would then create critical mass for real change.

Fourteen participants strongly agreed or agreed with this idea. Under strengths and opportunities participants wrote:

- research begun to gauge level of public understanding
- need partners in industry to pilot and evaluate
- we need to have clarity about what we are doing and this needs to be a whole-of-community approach
- overcoming adversity is a human experience – we get resilience from it
- needs to be lived experience led.

Under concerns and weaknesses the following statements were written:

- consumers need belief in themselves with training
- maybe not call it 'recovery'.

Idea: Community radio / TV / newspaper change culture first to inclusive

Eleven participants either strongly agreed or agreed with this idea. Four participants indicated neutrality. Under strengths and opportunities the following statements were made:

- use local radio and local papers
- develop key contacts – local mayors, youth and creative spaces
- important that this raises awareness and provides voice.

Under concerns and weaknesses that following statements were made:

- where does the funding come from?
- media messages need to be carefully worded to achieve desired outcomes
- as long as it is lived experience voices and not professionals.

Conclusion

The Forum enabled extensive discussion between a wide variety of stakeholders as recorded in this report. While the Commission has responsibility under the whole-of-government Strategic Plan to lead work on this issue it also requires public, private and non-government organisations to commit to undertaking action for change to occur. The Commission over the coming months will progress this issue as part of its ongoing commitment to embedding lived experience in system co-design. The Commission would be interested in working with stakeholders from and beyond the Forum to examine ways in which one or more of the ideas presented at the Forum could be progressed.

Attachment 1 Agenda

Promoting Lived Experience in Mental Health Forum

Date: Friday 29 July 2016
 Time: 10:00am – 2:00pm (arrival time 9:45am)
 Venue: Gambaro Function Room, Brisbane Common Ground
 15 Hope Street, South Brisbane

Time	Item	Lead
10:00am	Welcome and introduction to forum	Lesley van Schoubroeck, Commissioner, Queensland Mental Health Commission
10:10am	Facilitator introduction to the forum's program and housekeeping	Michelle Feenan, Engagement Plus
10:20am	Promoting lived experience address	Dr Louise Byrne, Lecturer, Lived Experience Mental Health, Central Queensland University
10:40am	Q&A – Promoting lived experience	Michelle Feenan, Engagement Plus
11:00am	Facilitated Discussion	Michelle Feenan, Engagement Plus
12:00pm	Lunch	
12:30pm	Facilitated Discussion	Michelle Feenan, Engagement Plus
1:45pm	Next steps and close	Lesley van Schoubroeck, Commissioner, Queensland Mental Health Commission

The key themes for the facilitated discussion will relate to:

- the opportunities for lived experience participation in the mental health system
- the major barriers to lived experience participation from the perspective of different stakeholders
- the potential options for addressing those barriers and who would be best placed to lead them
- identifying which options are most needed and most likely to be viable and effective

If you have queries in relation to the Forum please contact Josephine Peat, Senior Policy Advisor, Queensland Mental Health Commission on 3033 0312 or via email at Josephine.peat@health.qld.gov.au.

Attachment 2 Attendees

Name	Position and organisation / Consumer representative
Janice Crosbie	Consumer representative, Queensland Mental Health and Drug Advisory Council
Karen McCann	Acting Director, Social Inclusion and Recovery, Metro South Addiction and Mental Health Services
Helena Roennfeldt	Consumer representative
Michael Burge	Toowoomba Mental Health Service / Consumer representative
Julie Acton	Consumer Participation Officer, Neami
Tanya Miller	Queensland State Manager, Neami
Kris Trott	Chief Executive Officer, Queensland Alliance for Mental Health
Noel Muller	President, Queensland Voice
Kim Archer	Chair, Australian College of Mental Health Nurses – Queensland Branch
Maria Model	Project manager (NDIS) Aftercare
Eschleigh Balzamo	Manager, The Brook RED Centre
Nathan Bollard	Senior Manager, FSG Mental Health Services, FSG Australia
Marj Bloor	Executive Officer, ARAFMI QLD
Damian Perrin	Chief Executive Officer, Senior Recovery Mentor, Richmond Fellowship Queensland
Mitra Khakbaz	Executive Manager, Multicultural Development Association
Betti Chapelle	Senior Manager, Culture in Mind, Multicultural Development Association
Janet Martin	Mental Health, Alcohol and Other Drugs Branch, Department of Health
Jenny Speed	Consumer representative
Helen Glover	Director, Enlightened Consultants
Jane Smith	Community Visitor, Public Guardian
Louise Byrne	Lecturer in Lived Experience, Central Queensland University
Michelle Edwards	Carer Consultant, Mental Health and Specialist Services, Gold Coast Hospital and Health Service

Queensland Mental Health Commission

Name	Position
Lesley van Schoubroeck	Queensland Mental Health Commissioner
Josephine Peat	Senior Policy Advisor