Promoting Lived Experience Perspective: Discussion paper prepared for the Queensland Mental Health Commission

Purpose

This paper has been developed to prompt thinking and discussion on ways to promote lived experience participation in Queensland's mental health sector.

What do we mean by lived experience?

For the purpose of this paper, 'lived experience participation' refers to the many ways people with a personal experience of mental illness, service use and recovery are participating in the design and delivery of mental health services.

Participation may occur in a broad range of ways from board and advisory group membership, systemic advocacy positions, education and one-on-one support roles. Participation includes any role, paid or voluntary that specifically requires a perspective informed by a personal experience of mental illness and healing, regardless of whether symptoms do or do not continue.

The participation of people with a lived experience of suicide; alcohol and other drugs; or family, friends and carers of people with a diagnosis of mental illness is acknowledged as equally important in service design and delivery, but is not specifically considered in the context of this paper. It is recognised that the views and needs of people with mental illness and those who support them can differ substantially. Consequently, exploration of participatory roles for families, carers and supporters need to be considered separately from those for people with a personal experience of mental illness. Similarly, not all people with a lived experience of suicide may identify as having a mental illness. It is also recognised that many people with an experience of problematic alcohol and other drug use may not identify as having a mental illness.

Background

The lived experience or 'consumer' movement is a human rights movement. Empowerment and participation by people with a lived experience is considered essential internationally to progress this human rights agenda [1]. Australian mental health policy has promoted lived experience participation since 1992[2]. In the following decades, governments have insisted on more measurable participation by people with a lived experience in service delivery and planning, including an expansion of paid lived experience roles.

The National Standards for Mental Health Services provide clear directions to actively engage people with a lived experience in participatory roles. Similarly, the release of the next version of the Safety and Quality standard 2 'Partnering with consumers' is anticipated to place increased emphasis on the need for meaningful collaboration with people who have a lived experience, further supporting a shift towards all health organisations incorporating lived experience perspectives in tangible ways.

The Queensland Mental Health, Drug and Alcohol Strategic Plan 2014-19 includes a shared commitment across all sectors of the mental health system to support the active engagement and leadership of individuals with a lived experience across all levels of policy, legislation, planning and programs design, service delivery and evaluation.

Despite increasing insistence on lived experience participation, evidence suggests the mental health

sector struggles to incorporate lived experience in meaningful ways [3].

Here we review the growing international evidence that highlights the essential role of people with a lived experience within the mental health sector, and the potential benefits of lived experience participation to the mental health system. Possible future directions for promoting lived experience in the mental health system are also identified.

Benefits of Lived Experience participation

Lived experience knowledge is broader than an experience of illness and encompasses understanding of marginalisation, oppression and discrimination. Underpinning lived experience perspectives include shared understanding of loss or changes to social status/inclusion; relationships; employment and concepts of self as a result of diagnosis and service use [4]. Significantly, people with their own lived experience have also had periods of healing and wellness, regardless of whether they re-experience challenging times, and can provide practical advice on strategies for recovery.

Lived experience roles that embed the perspective of people with a lived experience in service delivery have been shown to improve outcomes for people using services in ways that can be measured from both clinical and recovery perspectives [5]. An emerging evidence base indicates support provided by people with a lived experience can be as effective in terms of symptom reduction and service satisfaction as care provided by mental health professionals [6]. Further, growing research suggests lived experience provides some benefits not found within traditional services [7]. People with their own lived experience do not have the same power imbalances commonly found in service provider/service user relationships [8], and can actively challenge existing power dynamics to promote the development of more equitable, collaborative therapeutic relationships. People with a personal lived experience can empathise and advocate on behalf of those currently unable to do so. Lived experience roles have also been found to reduce coercion within services and increase the human rights of consumers [9].

Research indicates lived experience provided services, particularly peer roles, contribute to an improved sense of hope, empowerment and social inclusion for those accessing services [10]. Social inclusion and connectedness was found to include improved interpersonal relationships and contribute to a sense of positive culture that fostered feelings of belonging and decreased social isolation. Additionally, lived experience involvement increased social confidence and boosted self-esteem in obtaining employment. Simply meeting someone who has overcome similar experiences can provide a living example of hope to those currently facing challenges [11]. Lived experience roles not only provide hope, they understand its absolute importance. In the immortal words of lived experience pioneer Pat Deegan:

> *For those of us who have been diagnosed with mental illness and who have lived in the sometimes desolate wastelands of mental health programs and institutions, hope is not just a nice sounding euphemism. It is a matter of life and death* [12].

The cost of mental illness on the economy is enormous, with lost productivity in Australia estimated at more than $10b p.a. and the overall direct cost of support for people with a mental illness estimated at $28.6b p.a. [13]. Some studies have shown overall service expenditure can decrease as a result of lived experience involvement. There is growing evidence that employing people with a lived experience in mental health inpatient settings may reduce the length of hospitalisation [14]. Considering the high cost per day, per bed, this is potentially a significant cost saving.

All these benefits potentially contribute to more positive recovery outcomes for people accessing services.

Guiding and leading the implementation of Recovery oriented practice

Recovery is a concept that has been developed and championed by people with a lived experience of mental illness. Recovery concepts challenged the previous paradigm that insisted mental illness was unremitting and chronic.

Recovery focuses on enhancing the individual's existing strengths rather than emphasising deficits and works collaboratively with the individual, rather than prescribing an externally determined and managed course of treatment. Core recovery concepts include;

- Hope and belief that an individual may design a meaningful life of their own choosing, beyond the limitations of 'illness'
- Empowerment, education and autonomy to ensure the needs of the individual are being met and they are enabled to guide their own healing journey
- Respecting the role of spirituality – whatever that means for the individual
- Acknowledging and actively addressing the need for community, social inclusion and connection with others.

People with a lived experience have been promoting the concept of recovery for over 150 years and have a deep internal and collective understanding of what recovery means and feels like. Since the 1970s the lived experience movement has contributed significantly to the push towards a recovery orientated mental health system.

Since the early 1990s Australian Government policy mandated a move towards recovery orientated service delivery. However, recovery implementation is acknowledged to be emergent and in many places lacking in effectiveness. Much of this could be attributed to confusion within the mental health sector as to what recovery is and how it can be implemented meaningfully [15].

In recent years lived experience roles aimed at supporting adoption of recovery oriented practice in mental health have increased. The validity of lived experience leadership in recovery education and implementation is supported by both research and industry trends, demonstrated by the appointment of lived experience Deputy Mental Health Commissioners in NSW and nationally, as well as executive level appointments to support recovery in a number of non-government and Queensland Health mental health services in Queensland.

Existing and Future scope of Lived Experience participation

Lived experience roles in mental health care

Lived experience workforce development is occurring rapidly in the U.K., Canada, United States, New Zealand and Australia. Lived experience roles, particularly peer support workers, have flourished within diverse settings in different countries. Peer support workers are employed in direct service roles to walk with others on their recovery journey: one-on-one or in groups. Until recently peer roles were predominantly found in the non-government sector.

The federally funded Personal Helpers and Mentors (PHaMs) program guidelines stipulates employment of at least one peer support worker within each PHaMs service nationwide. More

recently within the government sector, peer workers are being employed within Community Care Units (CCU) to assist people as they transition from hospital back into the community.

Although significant development has occurred, currently Australia has a less developed peer workforce than some countries. In America, certified peer specialists are now available in selected states as a government subsidised service through Medicaid, a means-tested health program providing affordable health care for low income families [11].
Peer work in America is increasingly seen as an integral part of moving toward a recovery oriented system. The following quote demonstrates perceived value and comes from the executive director of the American National Association of State Mental Health Program Directors, Robert Glover:

> *Consumers and peers are invaluable to the future public mental health system. Not only do they have a role to play, but they should be at the table in all aspects of our system* [16].

If Australia were to follow America's lead, the ability for peers in Australia to become Medicare providers could create great opportunity for community based lived experience support to become more available. The Better Access program in Australia already facilitates access to other types of mental health care through Medicare.

The wider expansion of peer roles in Australia's mental health system has been advocated within recent national reports. The National Mental Health Commission's review of mental health programmes and services also identified increasing the peer support workforce as a recommendation for reform.

Advocacy at a systemic, service and policy level has significantly increased the perceived value and uptake of peer work for NSW's Flourish, who are now asking 'why not a peer worker' for every role within the organisation. Flourish currently employ over 100 peer workers and are aiming for half their workforce as designated lived experience roles.

The recent signing of the NDIS Bilateral Agreement for Queensland creates new potential for the uptake and expansion of peer roles. It is anticipated people with a mental illness who are eligible for the NDIS will be able to access peer support as part of an individual package, as long as they are aware that peer support is an option. The Mental Health Council of Australia has pledged to assist capacity building of the peer support workforce to assist access for NDIS participants. The NDIS website identifies the need to create additional support items to include mental health peer workers as a specific support for mental health participants, results of which are presently outstanding [17].

Peer-run services
Peer-run services have been at the forefront of promoting lived experience support roles in mental health care. Nationally Queensland has provided some leadership in this area with three lived experience/peer run services;

- BrookRED in Brisbane
- PEARL (managed by FSG Australia) on the Sunshine Coast
- POS (Peer Operated Service) managed by Flourish in Hervey Bay

Although evidence relating to peer run services is sparse, the available research suggests lived experience or peer run services provide significant benefits to lived experience employees including ongoing and appropriate supervision, training and support and less co-opting of lived experience roles than is commonly found in mainstream services, where the peer role may be less understood [18].

Lived experience advisory roles

Lived experience or 'consumer' representation on forums, boards and advisory councils at local, state and national levels is common within the mental health sector. Lived experience representatives are often voting or deciding members of committees, forums or boards of government, non-government, industry or professional organisations. Lived experience representation aims to ensure the perspectives, priorities, interests and concerns of people accessing services are presented and protected. Representative roles ensure accountability and typically report back to the group they represent.

Research and education

Lived experience participation and leadership in research has been an identified target in the U.K. for some time. Research has identified issues of importance to organisations/services and funding bodies differ to those of people accessing mental health services [19]. Lived experience researchers ensure the correct questions are being asked and the priorities of people accessing services are being addressed.

Lived experience participation is increasing within higher education settings. In a recent survey of 32 Australian Universities, 75% included some lived experience involvement in mental health nursing education. However the degree of involvement, particularly input into curriculum, was highly variable. While most lived experience involvement was sessional, there are a small but rising number of substantive lived experience academic positions in Australia, leading to greater lived experience representation in both teaching and research.

The University of Melbourne was the first to establish a lived experience academic role over a decade ago. This role still exists and research into this role has provided the impetus and for further development at other institutions.

Recent research exploring a full-time lived experience academic role at CQUniversity in Queensland revealed overwhelmingly positive responses from participants, as the following quote illustrates:

> *I can say hand on my heart that this has been the best course I've done... It has changed me as a person and the [way] I approach every person. It had a profound impact [on me].* [20]

As a result of these positive findings, the lived experience led course became a core or compulsory subject with the undergraduate nursing degree. In time, due to the success of the role and high student numbers, a second fulltime lived experience academic and several casual roles have been developed at CQUniversity. Curtin University in W.A. and the University of South Australia have also appointed part-time lived experience academic roles. Further, initiatives like the annual International Service Users in Academia Symposium and the NSW Consumer Led Research Network aim to encourage and increase lived experience participation and leadership in academia.

Despite these significant appointments and developments, academic roles are largely isolated, with few lived experience academic positions within Australia or internationally. As research suggests, greater lived experience leadership in the formal education and workplace training of mental health professionals would likely result in greater understanding of recovery principles by clinicians, less stigmatising/discriminatory attitudes and subsequently, better outcomes for people accessing services.

Challenging Stigma/Discrimination

Many studies have reported the important role of people with a lived experience in challenging stigma/discrimination [21]. The act of being 'out and proud' has been found to challenge the notion that there is something fundamentally 'wrong with' or 'different' about people facing mental health issues. The visibility of people with a lived experience also challenges the code of silence that typically surrounds mental health issues and lets others facing mental health issues know they are not alone.

Because of discriminatory attitudes still attached to mental health issues, many people do not talk to their usual support networks and delay seeking professional help. This leads to isolation and mental health issues becoming significantly worse by the time any assistance is sought [22]. Wide scale use of people with a lived experience being 'out and proud' could contribute to a dramatic change in societal attitudes towards mental health issues, potentially leading to less isolation, lower suicide rates and lower incidence of severe or persistent mental illness.

The 'Coming Out Proud' program supports people to make informed decisions about their readiness to come out with mental health challenges. This program is based on decades of research, facilitated by people with a lived experience, and provides a whole-of-community focus by potentially empowering many people within a range of communities to have the courage to speak about their experiences [21].

Rural, Remote and Regional Settings

Providing appropriate mental health care to meet the needs of people in rural, remote and regional areas continues to be a challenge. It is particularly difficult to attract and retain professionally trained staff to rural and regional areas [23].

Currently few lived experience roles exist in rural and regional settings. Those that do exist show promising results. The 'Peer Perspectives Program' run by Uniting Care in South Burnett provides peer support to people in drought affected areas and has received positive feedback from those who've accessed it.

While the development of lived experience roles in rural, remote and regional areas would not replace the need for mental health professionals, an increase in lived experience roles may have the potential to make a positive difference in these areas [24]. People with a lived experience recruited locally, are committed to the area and understand the unique perspectives, culture and challenges of rural life. Initiatives like the successful 'Men's Shed' also demonstrate that men are more likely to open up about health and mental health issues in less formal, peer support settings.

Beyond Mental Health Settings

There is evidence to indicate the value in exploring lived experience roles beyond mental health settings, to consider education and liaison roles within emergency services, housing, employment and primary and secondary schooling. In one of the more innovative examples, people with a lived experience were employed to assist people with mental health challenges to re-enter the workforce. Within this project, people already working in peer roles were taught the core competencies of a supported employment model.

Despite ongoing training, the peers had no specialised education or background in the area of employment support. The peers were also performing in their substantive roles whilst fulfilling the role of employment specialist, creating a very high workload. Despite these barriers, research found the peers performed at average or above average levels, which was considered encouraging. The findings also indicated participants saw the peers as role models and this helping participants over-

come self-stigma, consequently improving their confidence in finding and retaining employment [25].

As an early-intervention and long range prevention strategy, people with a lived experience providing education to primary and secondary students could encourage more open conversation about mental health. This could help to normalise mental health challenges, encourage more support within existing networks and potentially decrease the number of people seeking service provision.

It is possible that wide scale recovery education led by people with a lived experience could also empower friends, families and communities to better understand and support people with mental health challenges. Better understanding and support within communities, particularly around concepts of hope and belief, could also contribute to more people receiving support earlier, eventually taking some of the onus off service providers and ultimately reducing the incidence of acute mental illness.

Barriers and Enablers

Despite the many benefits of lived experience participation, barriers to development are identified throughout the literature. Supportive factors that assist or enable are also identified.

Credibility and professional isolation

Lack of credibility in the eyes of mental health professionals has contributed to common experiences of professional isolation, marginalisation and tokenism particularly within traditional services [26]. A clearer role for lived experience workers in the leadership of recovery implementation has been one recommendation to address this issue [27].

Wide scale training on the value of lived experience roles has also been suggested to lessen the stigma/discrimination frequently faced by lived experience workers [28]. Similarly, increasing the numbers of lived experience workers within an organisation and ensuring access to lived experience networks and supervision has been proposed to counteract issues of isolation and discrimination.

Organisational environment

Research indicates senior manager attitudes as critical to the success of lived experience participation [29]. Several studies cited commitment to lived experience participation in the form of organisational leadership as the most essential ingredient in the successful inclusion of lived experience roles. The attitudes of senior managers were found to influence the wider workplace culture, aiding collaboration and inclusion of lived experience roles within the workplace [29].

Supportive or enabling factors were identified when the organisation was truly willing to accommodate the lived experience worker and had a willingness to make structural and procedural changes [6]. In best practice examples, services utilised the lived experience roles to intentionally work towards change, particularly better recovery uptake and better responsiveness to service user needs.

Reasonable accommodations

Organisations that were inclusive of lived experience frequently offer 'reasonable accommodations' which allow some flexibility in the roles. The degree of formality with these arrangements and what the flexibility looks like depends on the service and type of role but may include the ability to work from home, or have reduced hours when needed that can be caught up later [30]. Having this flexibility aids the sustainability and success of the roles. Organisations adopting these practices

commonly began by considering flexibility for lived experience specifically but often extend the benefit to all employees, contributing to more inclusive workplace culture.

Workforce development

An inconsistent approach to workforce development has been identified as a potential barrier to the promotion of lived experience roles in Australia. There is a need to address issues of remuneration, career pathways, articulated position descriptions and access to appropriate supervision. A lack of identifiable national leadership and divergent ideas within the lived experience movement about workforce development has also been cited as potential barriers in a number of studies.

The role of professional education and training for lived experience roles has been a source of significant disagreement within the lived experience movement. There are particular concerns about peer workers being 'co-opted' or forced into mimicking traditional mental health roles [31]. There is also concern that training requirements for peer positions could act as a barrier to people being able to enter lived experience roles.

Accredited training has been seen as potentially increasing the acceptance of the roles, chiefly by academically trained mental health colleagues. However, concerns have been raised that accreditation could undermine or diminish the ways of knowing and viewing that make lived experience work unique [32].

Specialised training developed by people with a lived experience is seen as a positive way of avoiding co-opting [31]. The nationally accredited Cert IV in Mental Health Peer Work has sought to address this concern by having core content designed and delivered by people with a lived experience.

An example of lived experience devised and developed training is Intentional Peer Support (IPS) which is one of the few lived experience courses available internationally. IPS has recently been listed as a training recommendation for peer workers within the Queensland Government's CCU (community care unit) model of service and includes a focus on:

- Hope as a core perspective
- Mutual responsibility within the relationship, with both people ultimately being transformed by the relationship rather than the traditional 'helper' relationship commonly found in services
- Moving towards what is wanted rather than away from what is not wanted
- Acknowledgment of different world views and working intentionally towards a shared world view and ability to communicate and connect more effectively [4]

A variety of other peer support approaches with similar underpinning principles have developed across diverse settings. Many services use a mix of peer devised tools and approaches, adapting and adopting to best suit the needs of the individual context. Reports indicate the effectiveness of this strategy is largely dependent on whether the choices and adaptions are made to serve organisational goals and maintain pre-existing service priorities, or are focused on best outcomes for the person accessing the service.

Placement of peers in less traditional settings, with the willingness or flexibility to be inclusive of lived experience priorities, has been raised to ensure co-opting of peer staff is minimised or avoided [18]. One suggestion proposes 'housing' peers within peer-run settings and working within more traditional services a few days a week to provide a primary work environment that understands and supports the roles as well as access to appropriate networks and supervision.

The great diversity of lived experience roles encompassing one-on-one or group peer interactions; systemic advocacy; committee, forum and board representation; education and research as well as

the complexity of these positions, suggest the need for a diverse range of lived experience professional development activity to meet different roles and settings.

Increasing the Evidence Base

Although an emergent evidence base exists, more robust research is needed to demonstrate the value and embed lived experience roles within the mental health sector, particularly to increase the credibility and acceptance of lived experience participation. It is critical that research into lived experience participation includes lived experience leadership in the research design, process and reporting [33].

Co-production and Lived Experience Leadership

Co-production with allies from other disciplines is critical to the success of lived experience roles. However, research cautions that co-production must ensure lived experience voices have equal weighting and be enabled to lead in areas that are appropriate – particularly regarding recovery orientated concepts and the needs and priorities of people accessing services [27]. Lived experience participation at all levels of the system, including executive management roles is increasing across the sector and is believed to be essential to allow lived experience perspectives authority and impact. The need for leadership has been highlighted by the pending development of a Lived Experience Leadership Academy based at Yale University, America.

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This paper has been prepared for the Queensland Mental Health Commission by Dr Louise Byrne, Lecturer in Lived Experience Mental Health, CQ University Australia.

Selected References

A complete list of references including international review of literature is available on request

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