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INQUIRY INTO THE OPPORTUNITIES TO IMPROVE MENTAL HEALTH OUTCOMES FOR QUEENSLANDERS

SUBMISSION BY THE PEER PARTICIPATION IN MENTAL HEALTH (PPIMS) NETWORK IN BRISBANE NORTH

4 February 2022

This Submission was prepared by Tina Pentland (author) with Paula Arro (PPIMS Secretariat)

Acknowledgements

We would like to acknowledge the traditional owners of the lands across Queensland on which we live and pay our respects to elders past, present and emerging.

We acknowledge the support of people with a lived/living experience of mental health issues to the PPIMS network, without whom it would not exist, and thank the PPIMS members who have contributed to this Submission. We recognise their vital commitment to improving mental health outcomes for all and value their courage to do this.

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Note on language

The terms lived experience, lived/living experience, consumer and carer have been used throughout. While the term lived/living experience is currently the preferred usage for people with a lived experience of mental health issues, the terms consumer and carer, which denote people with a lived/living experience and the family members and friends who support them, are used extensively in the Queensland mental health system.

Our Submission

The importance of lived experience to improving mental health outcomes and fostering recovery, especially with regard to stigma reduction and peer support, was clearly articulated in the Fifth National Mental and Suicide Prevention Plan.[1] The momentum for greater participation in the mental health system by people with a lived or living experience (PLE) has moved on substantially since then so that PLE now contribute to every aspect of the mental health system – through the peer workforce, education and training, employment, community awareness programs, advocacy and policy development. Their contribution to reform is also acknowledged in the many state and federal reports, plans and guidance materials that have been released in recent years – such as the Productivity Commission[2] and the Royal Commission into Victoria's Mental Health System.[3] The special role of peer workers – who draw on their unique experiences of mental or emotional distress, or experiences of supporting another person experiencing mental health challenges, to build relationships that are based on 'collective understanding of shared experiences, self-determination, empowerment, and hope' – is set out in detail in the recently released National Lived Experience (Peer) Workforce Development Guidelines.[4]

Since 2016, the Peer Participation in Mental Health Services (PPIMS) network has built a strong foundation in Brisbane North to nurture a proactive and informed peer workforce, to advocate for consumer and carer engagement in policy development and planning, and to build healing relationships among individuals and with the community. This Submission by the PPIMS network to the Mental Health Select Committee Inquiry addresses the Terms of Reference with respect to **(d) the experiences and leadership of people with lived experience of mental illness, problematic substance use and suicidality, and their families and carers**, **(c) opportunities to improve economic and social participation**, and **(i) relevant national and state policies, reports and recent inquiries**.

Our Submission is set out as follows:

1. Background
2. The Peer Participation in Mental Health Services (PPIMS) Network
    a. Consumer and Carer Engagement
    b. Lived Experience Workforce Development
3. Have Your Say: Contributions by PPIMS Network Members
4. Summary and Recommendations

[1] Council of Australian Governments. 2017. The Fifth National Mental Health and Suicide Prevention Plan. https://www.mentalhealthcommission.gov.au/getmedia/0209d27b-1873-4245-b6e5-49e770084b81/Fifth-National-Mental-Health-and-Suicide-Prevention-Plan

[2] Productivity Commission Inquiry Report. 2020. https://www.pc.gov.au/inquiries/completed/mental-health/report

[3] Royal Commission into Victoria's Mental Health System. 2021. Final Report. https://finalreport.rcvmhs.vic.gov.au/download-report/

[4] National Mental Health Commission. 2021. National Lived Experience (Peer) Workforce Development Guidelines, p. 4. https://www.mentalhealthcommission.gov.au/getmedia/a33cce2a-e7fa-4f90-964d-85dbf1514b6b/NMHC_Lived-Experience-Workforce-Development-Guidelines

Background

Despite extensive investment and reform programs over the past thirty years, the prevalence of mental ill health has not fallen, and the burden of disease remains.[5] It is a burden that impacts individuals, families and the wider community. In fact, instances of mental ill health and the need for services and supports have continued to grow as a consequence of the Covid-19 pandemic.[6] During 2020 and 2021, findings from federal and state inquiries such as the Productivity Commission Inquiry[7] and the Royal Commission into Victoria's Mental Health System[8] have been published and their final reports have been released. While the social and economic costs of mental ill health are well documented in these reports and elsewhere,[9] they also highlight the importance of lived experience as an essential component of mental health care and recovery, both in terms of peer workforce development and consumer and carer engagement.

At its basis, recovery is about people (not systems), where the goal is for individuals, and the communities they live in, to maintain social and emotional wellbeing. As stated by the World Health Organization, recovery is about people with a lived experience of mental ill health 'regaining control of their identity and life, having hope for their life, and living a life that has meaning'.[10] Within this framework, the recovery approach to social and emotional wellbeing must address 'the social determinants that impact on people's mental health, including relationships, education, employment, . . . [and] community'.[11]

In summary, these are the core principles of lived experience engagement and participation.

The Fifth National Mental Health and Suicide Prevention Plan[12] noted that 'peer workers or workers with a lived experience of mental illness, play an important role in building recovery-oriented approaches to care'. The Queensland Mental Health Commission similarly states that a thriving lived experience workforce is a 'vital component of quality, recovery-focused mental health services'.[13]

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[5] Queensland Mental Health Commission. 2022. Briefing Paper: Inquiry into the opportunities to improve mental health outcomes for Queenslanders. https://documents.parliament.qld.gov.au/com/MHSC-1B43/IQ-5DEF/220114%20-%20Queensland%20Mental%20Health%20Commission%20written%20brief.pdf

[6] For example, calls to Lifeline have increased by 20% each year since 2019: Media Release, 20 August 2021, https://www.lifeline.org.au/media/0olpjjfq/20210820-australians-reaching-out-for-help-in-record-numbers.pdf

[7] Productivity Commission Inquiry Report. 2020. https://www.pc.gov.au/inquiries/completed/mental-health/report

[8] Royal Commission into Victoria's Mental Health System. 2021. Final Report. 2021. https://finalreport.rcvmhs.vic.gov.au/download-report/

[9] E.g., Queensland Mental Health Commission. 2017. Shifting minds: Queensland Mental Health Alcohol and Other Drugs Strategic Plan 2018-2023. https://www.qmhc.qld.gov.au/2018-2023-strategic-plan

[10] World Health Organization. 2021. Guidance on community mental health services: Promoting person-centred and rights-based approaches, p. 5. https://www.who.int/publications/i/item/9789240025707

[11] Ibid.

[12] Council of Australian Governments. 2017. The Fifth National Mental Health and Suicide Prevention Plan, p. 46, https://www.mentalhealthcommission.gov.au/getmedia/0209d27b-1873-4245-b6e5-49e770084b81/Fifth-National-Mental-Health-and-Suicide-Prevention-Plan

[13] Queensland Mental Health Commission. 2022. Briefing Paper: Inquiry into the opportunities to improve mental health outcomes for Queenslanders, p. 31. https://documents.parliament.qld.gov.au/com/MHSC-1B43/IQ-5DEF/220114%20-%20Queensland%20Mental%20Health%20Commission%20written%20brief.pdf

At a local level, the Peer Participation in Mental Health Services (PPIMS) network provides opportunities for education, training and employment in Brisbane North and advocates for lived experience representation at every level of policy, planning and service delivery, encapsulated in the words: *'nothing about us without us'*.

The next section introduces the PPIMS network and briefly describes recent initiatives that clearly illustrate how lived experience engagement and participation can transform mental health care in the community and promote personal recovery. This brief overview with case studies also demonstrates beyond any doubt that major reform in this area needs a strong commitment by government that is backed up with funding to achieve the meaningful changes that are needed to improve mental health outcomes for all Queenslanders.

The Peer Participation in Mental Health Services (PPIMS) Network

The PPIMS network was formed in 2016 to be a voice for consumers and carers with lived experience in the Brisbane North region. PPIMS has a clear commitment to, and leadership in, consumer and carer engagement at every level of the mental health system, and strongly advocates for the lived experience voice to inform mental health policy and the development of services. PPIMS is recognised as a leader in the field of peer engagement not only in Australia, but internationally.[14]

PPIMS membership consists of people with a lived/living experience (PLE) of mental health issues in the community, including consumers and carers, peer workers and general mental health workers, volunteers, trainers and educators, students and academics, and committee representatives. PPIMS, therefore, brings together a diverse range of PLE through regular network meetings, newsletters and forums, hence providing a unique opportunity in the community for people to connect, to access training and employment, and to contribute to system reform across the Brisbane North region. Such opportunities for social and economic participation, which have evolved over time as the network has grown, reflect the wider aim of the Productivity Commission to improve social and economic participation through mental health reform.[15]

Prior to the COVID-19 pandemic, PPIMS meetings were held monthly in two locations, at Brisbane North PHN's Lutwyche and North Lakes offices, to cater for members who live across a large region extending from inner Brisbane to Moreton Bay and beyond. Since early in 2020, most meetings have been held remotely via Zoom.

In summary, the PPIMS network improves PLE engagement and participation by:

- supporting PLE who want to actively participate in the mental health system reform process and/or are accessing mental health services;
- providing opportunities to have regular updates and input around services, policy, and program and system developments;

[14] Marie-Pascale Pomey, Jean-Louis Denis and Vincent Dumez (Eds.). 2019. *Patient Engagement: How Patient-provider Partnerships Transform Healthcare Organizations*. Palgrave Macmillan.
[15] Productivity Commission Inquiry Report. 2020. https://www.pc.gov.au/inquiries/completed/mental-health/report

- providing opportunities to have regular updates on current and emerging issues and identify strategies to improve engagement, participation, training and employment opportunities;

Well-educated people with a lived experience is the key.

- providing advice on emerging issues faced by consumers and carers in the mental health sector;
- encouraging participation in co-design opportunities that arise through Brisbane North PHN or other government and/or non-government services; and
- providing a safe space for PLE to voice their opinions and feel supported and understood.

In a post-meeting survey after the first PPIMS meeting in April 2016, attendees were asked to say what they were hoping for from this new network. Overwhelmingly, their responses reflect what PPIMS actually does, namely:

- provide an opportunity to meet others,
- share information and views,
- identify training opportunities,
- look for opportunities to collaborate,
- find local activities/events,
- make contacts,
- find employment in the mental health area, and
- find out what services are in the Brisbane North region.

The network has two principal areas of focus: (1) consumer and carer engagement and (2) the lived experience workforce.

Consumer and Carer Engagement

There has been no consumer peak body for over five years in Queensland, and the proposed new lived experience peak, which is being developed by the Queensland Mental Health Commission, is still not up and functioning more than two years since it was announced in 2019. In other words, there is currently no representative body to advocate for lived experience at the state level.

This has had a serious impact on the ability of PLE to have a collective voice and a seat at the table with the Queensland Government.

In a voluntary capacity, local and regional networks have attempted to advocate and engage with state government, in particular, with the Mental Health Branch and the Queensland Mental Health Commission, but have seen little genuine investment into embedding lived experience engagement and further developing the peer workforce. What we have seen is reports, strategies and research being funded, but with no commitment or investment

towards rolling out implementation. Where work has been done, it seems to have been done internally within the system and little information is made available to consumers and carers in the community who want to engage. Where work has been done externally, it has duplicated work and efforts already in place that have been developed through local PHNs with no investment or co-contribution from the state.

For example, in 2018 the federal Department of Health funded the Brisbane North PHN to chair and project manage the National PHN Mental Health Lived Experience Engagement Network (MHLEEN) whose aim is to embed lived experience engagement and workforce development in all of PHNs and commissioning of services. Other PHNs have since started to proactively develop in this space.

Due in part to the void created by the absence of a consumer peak and in part the lack of proactive programs by Hospital and Health Services (HHS/s), the PPIMS network, with the support of the Brisbane North PHN, has become a leader in the field of consumer and carer engagement. The different aspects of this are briefly described in the following sections.

Brisbane North PHN

The spirit of collaboration and proactive support for lived experience engagement that was modelled by Partners in Recovery in Brisbane North (2013-2016) has been continued without let-up by Brisbane North PHN. Through their vision and leadership, and recognising the importance of the collective knowledge and experience of PLE, Brisbane North PHN has empowered the PPIMS network to be a strong and independent collective voice.

Having PPIMS at my back and knowing I'm part of a wider network has really helped me.

A quarantined budget is allocated to PPIMS annually to cover sitting fees/honorarium payments for engagement work, and capacity building initiatives such as Certificate IV in Mental Health Peer Work and Voices for Change Speakers Training (with Brook RED) are regularly offered.

The opportunity to gain a Cert IV in Mental Health allowed gave me to gain employment.

Representation on Committees

As lived experience representatives, PPIMS members have had opportunities to contribute to – and indeed influence the design of – major programs and initiatives in Brisbane North, including:

- the Way Back Support Service at Redcliffe
- the Regional Plan, *Planning for Wellbeing*
- the mental health hubs in Brisbane North

- safe spaces in Brisbane North.

The Way Back Support Service

The Way Back Support Service was established in Redcliffe in 2017 following an extensive development process involving a partnership with lived experience representatives and community members, Brisbane North PHN, Metro North HHS, beyondblue, MIFQ/Richmond Fellowship[16] and the Australian Institute for Suicide Research and Prevention (AISRAP). Due to the success of this model, the service has since been extended to Caboolture.

The Regional Plan – Planning for Wellbeing

The Regional Plan of Brisbane North PHN – *Planning for Wellbeing* – was released in 2018. It was developed through working groups and extensive consultation involving PLE at every step. A significant feature of the Plan is the recognition of the role of PLE in every aspect of mental health service design and delivery. A commitment to making this a reality is demonstrated throughout the Plan, beginning with Chapter 1: **People with a lived experience leading change**. Chapter 1 sets the scene, therefore, with the result that workforce development, consumer and carer engagement and relationships, and commitment to building strong PLE representation are included in the shared objectives and actions of every chapter.

Mental Health Hubs (co-design)

The successful roll-out of the mental health hubs in Brisbane North followed an extensive co-design process such as all-day workshops and roundtable discussions involving all stakeholders and with significant lived experience input. The tender process and interviews also included lived experience representatives as panel members. The three hubs, located in the major hospital catchment areas (Royal Brisbane and Women's Hospital, the Prince Charles Hospital, and Redcliffe and Caboolture Hospitals), deliver integrated clinical and non-clinical services for people with severe mental illness.

Safe Spaces (co-design)

The co-design process to develop four safe space hubs in Brisbane North (inner Brisbane, Strathpine, Caboolture and Redcliffe) illustrate how lived experience can successfully guide and operate a major new initiative in the region. The hubs were developed through a dynamic co-design process led by Roses in the Ocean, itself a peer-led community organisation, with major input from those who experience emotional distress and suicidal crisis and the people who care for them, together with health professionals and other community representatives. The safe space hubs have been designed specifically to provide a peer-led alternative to hospital emergency departments for those who experience emotional distress and suicidal crisis; they offer support outside of normal business hours, outreach and in-reach to and from emergency departments, individual safety planning, sensory modulation and other therapeutic activities. An essential component of the model is ongoing support, supervision and mentorship of the lived experience workforce.

[16] MIFQ – Mental Illness Fellowship Queensland

Lived Experience Workforce Development

Lived experience work offers a valuable contribution to the mental health sector. This work is unique (i.e., it cannot be done by people who do not have a lived experience of mental ill health) and requires particular qualities of the individual, training and support.

The NDIS pool of workers attracts people with unacknowledged mental unwellness, looking for an 'easy' job. No qualifications required. This has serious implications for NDIS clients with mental illness.

The recently released National Lived Experience (Peer) Workforce Development Guidelines state that lived experience workers draw on their own experiences of mental or emotional distress as well as their experiences of service use and recovery, to 'build relationships based on collective understanding of shared experiences, self-determination, empowerment, and hope'.[17]

Lived experience workers are 'agents for change' who can help service providers 'understand everything in mental health care through the lens of lived experience and recovery'.[18] In order to achieve the benefits of this resource, 'the lived experience workforce needs to be well supported, sufficient in numbers and embedded across all areas of the mental health system'.[19]

The PPIMS network actively promotes these goals, and through its programs and activities has supported many PLE (consumers and carers) to enter the peer workforce. However, it is an uphill battle, given that the lived experience workforce in Queensland is very small and poorly supported. In 2020-21, the lived experience workforce in Queensland accounted for just two per cent of all FTE positions,[20] and these positions are not evenly distributed throughout the HHS regions.

A peer support worker believes that the individual's abilities to build resilience and be persistent as well as learning to deal with frustration are important outcomes of these interactions in difficult situations.

Lived Experience Peak Body

A key achievement building on Objective 1.1 of Chapter 1 of *Planning for Wellbeing*: **Strengthen and diversify the collective voice of people with a lived experience in order to drive service improvements** is the progression of the Queensland Framework for the

[17] National Lived Experience (Peer) Workforce Development Guidelines. 2021, p. 4.
[18] Ibid. p. 4.
[19] Ibid. p. 5.
[20] Queensland Health. 2022. Written briefing: Inquiry into the opportunities to improve mental health outcomes for Queenslanders. https://documents.parliament.qld.gov.au/com/MHSC-1B43/IQ-5DEF/220117%20-%20Queensland%20Health%20updated%20written%20brief%20-%20not%20embargoed%20information.pdf

Development of the Mental Health Lived Experience Workforce.[21] With no funded peak body advocating for the lived experience workforce, representatives from the PPIMS network alongside other key peer-led mental health organisations (Brook RED, Peach Tree Perinatal) worked together on a voluntary basis to create the Queensland Lived Experience Workforce Network (QLEWN).

Since 2018, QLEWN has endeavoured to work with the Queensland Mental Health Commission, outlining recommendations for lived experience workforce development from research done by the Commission. Further negotiations led to a commitment to progress this work, which was undertaken by researchers at RMIT University, and the Queensland Framework was subsequently released in 2019. However, to date there has been no clear investment in the promotion and implementation of the framework. QLEWN, a voluntary group, has since partnered with the Queensland Alliance for Mental Health (QAMH) and the Community Services Industry Association to try to gain the commitment that is needed to proceed with this framework.

QLEWN is committed to progress the agenda of the lived experience workforce across Queensland, with identified priorities in sector leadership, education and training, and advocacy. Urgent investment into the peak body is required to ensure the sustainability of QLEWN to achieve its strategic goals.

Case Study: Peach Tree Perinatal Wellness – a peer-led organisation

The following story illustrates what can be achieved by PLE.

Peach Tree is a not-for-profit perinatal, infant and early parenthood mental health service which is totally peer led. The organisation was funded by Brisbane North PHN in 2017 and as a result went from being entirely volunteer run to employing 21 lived experience workers (9 FTE). Peach Tree is now embedded in services throughout Brisbane and operates three Parent Wellbeing Centres – encouraging emotional, social, and physical health and wellbeing, and acting as a community-based gateway into treatment and support options.

Have Your Say: Contributions by PPIMS Network Members

PPIMS supported me to do the CERT IV in Mental Health:

The most rewarding aspect of being a Peer Worker during 2019-2020 was to be given the opportunity to gain a Cert IV Mental Health which allowed gave me to gain employment. This has certainly been both rewarding, complex, challenging but at the same time given me an insight as to the needs of people in the community with a mental Illness.

Mental Illness is a huge speciality e.g., Youth & Adults, Aged Care, Alcohol & Drugs, Suicide Prevention, Grief, PTSD – the list goes on – and if we can educate people in these speciality areas, I feel this is a step towards good recovery, and well-educated people with a lived experience is the key and a foundation to support this.

[21] L. Byrne, L., Wang, H. Roennfeldt, M. Chapman and L. Darwin. 2019. Queensland Framework for the Development of the Mental Health Lived Experience Workforce. https://www.qmhc.qld.gov.au/sites/default/files/qmhc_lived_experience_workforce_framework_web.pdf

I would like to reproduce here this excerpt from the PPIMS Submission to the Productivity Commission (2019) as it addresses the current problem clearly:

The Peer Participation in Mental Health Services (PPIMS) network was formed to be a voice for people with lived experience (PLE) in the Brisbane North region. During the three years since its formation, PPIMS has been a strong support to PLE in Brisbane North by developing strong links to the community and community organisations, working with government and non-government organisations, collaborating in research state-wide and nationally, and many other projects. In 2018, members of the PPIMS network contributed through a robust and collaborative consultation process to the Regional Plan, *Planning for Wellbeing*, sponsored by Brisbane North PHN and Metro North Hospital and Health Service, in which PLE, including families and carers, are acknowledged as essential leaders of change. The purpose of the network, as the name suggests, is to enable participation for everyone and to work collaboratively to actively participate in mental health systems and reforms to achieve this objective, the network facilitates activities that provide a voice for PLE in the Brisbane North region, improve PLE engagement, provide information on current and emerging issues, and encourage participation in co-design opportunities through consumer and carer representation and engagement.

Lack of qualifications among NDIS support workers and a lack of support/mentoring for these workers, which has serious negative consequences for NDIS participants who are not getting the support they need.[22]

For four years l was a consumer and carer representative on several governance committees at Brisbane North PHN, advocating for the specialist treatment, care, and access for those with Borderline Personality Disorder. It was an uphill battle. My efforts did not influence policy. I became disillusioned, suffered burnout, and left the field.

Now as an NDIS participant (with a Cert lV in Mental Health and years of advocacy, knowledge and experience), trying to find a qualified support worker with lived experience is proving next to impossible.

In my experience, the NDIS pool of workers attracts people with unacknowledged mental unwellness, looking for an ‘easy’ job. No qualifications required. This has serious implications for NDIS clients with mental illness.

On two occasions, l, as an NDIS participant, have had to be the support person for the support worker as they were unqualified, and unaware of their own mental health issues and stigma. They were unfit for the role. One support worker mentioned she felt like she was the client, and that l was the sw.

Consequently, my needs as the client were not met. The time l spent with the support worker, for which they were paid, was spent supporting them. I was more qualified for the role than they were.

[22] See: Chapter 1, *Planning for Wellbeing*: Item 1.3: Identify, inform and gain feedback from People with a Lived/Living Experience and experiences with the National Disability Insurance Scheme (NDIS)

An excerpt of the submission by a former peer support worker and PPIMS network member is set out here. The complete submission is added as Attachment 1 .

LIVED EXPERIENCE WORKFORCE

I found Peer Support (PSWs) can be very rewarding personally and give you much pride in being a person helping another person with lived experience and in a vulnerable position with mental distress and helping their family or carer with information with supports in the community. And sometimes [it is] very frustrating due to being a casual worker with under-employment and with on call changing shift work and working two different peer support roles in the HHS and also working for an NGO. As a peer support worker I offered support and encouragement when things didn't go according to plan, as well as reassurance and understanding that feelings of frustration and disappointment were common experiences. A peer support worker believes that the individual's abilities to build resilience and be persistent as well as learning to deal with frustration are important outcomes of these interactions in difficult situations. On many occasions as a peer support worker I would be appropriately sharing with an individual and sometimes their family or carer that I'd had similar experiences and how I had dealt with these and learnt strategies and accessed wellbeing supports to help me manage my mental health. Peer support workers believe that by sharing that they had similar experiences, a safe space (e.g., in a group setting) can be created to talk about sensitive topics. These interactions were described as allowing these individuals to develop new coping and social skills as well as becoming more adaptable when facing adversity. The role is not without challenges, including a lack of clarity around the role, causing confusion, and lack of role credibility. The peer support worker's emphasis on shared engagement in everyday experiences aligns with the importance of personal recovery concepts. Personal growth and living a meaningful good life may be viewed differently to measures of clinical effectiveness/emphasis on symptom reduction. Difficulties defining and maintaining peer roles can be complicated within clinical settings where tension between recovery and the medical model may be more pronounced.

Summary and Recommendations

In summary, the importance of lived experience engagement and peer workforce development has been described; and the role of the PPIMS network and other peer-led organisations in promoting lived experience engagement and peer workforce development in Brisbane North has been outlined. The urgent need for greater funding and investment in this sector – in people, resources and commitment – is clear. The following recommendations seek a state-wide response by the Queensland Government and the Queensland Mental Health Commission and proactive engagement and investment in this vital but under-resourced area of the mental health system.

Recommendation 1 is drawn from work by PPIMS in developing and then reviewing Chapter 1 of *Planning for Wellbeing*, **People with a Lived Experience Leading Change**.
Recommendation 2 is drawn from the updated Chapter 2 of *Planning for Wellbeing*, **Supporting Families and Carers**, which was prepared by a working group of lived experience delegates working alongside Carers Queensland and Brisbane North PHN.

Recommendation 1

That the Shared Objectives and Actions in Chapter 1 of *Planning for Wellbeing*, detailed below, be adopted and coordinated at a state-wide level, with co-investment by PHNs.

Shared Objectives	Actions
1.1 **Our Collective Voice** Strengthen and diversify the collective voice of People with a Lived/Living Experience that drives service improvements.	• continue to support and resource the PPIMS Network to expand and build a consistent, independent and diverse voice that is a partner in the governance of the Plan • support and contribute to the building of a state-wide and national network of People with a Lived/Living Experience through peak body, professional development opportunities, co-design and advocacy • actively recruit a diverse group of People with a Lived/Living Experience into membership and leadership roles to participate in planning, delivery and evaluation of services, ensuring reach and engagement with People with a Lived/Living Experience in underserviced and hard-to-reach groups, including those who lack strong community connections.
1.2 **Building Capacity** Make available training and capacity building for People with a Lived/Living Experience to support the service system and build the capacity of the broader workforce.	• continue to investigate, collaborate and leverage off availability of subsidies, co-contributions and collaborative opportunities at a local, regional, state and national level • contribute to the development of mentoring, coaching, supervision and co-reflection opportunities for all • develop a register of People with a Lived/Living Experience available as speakers, educators, trainers, supervisors/mentors and researchers to support the service system and build the capacity of the broader workforce.
1.3 **Authentic Engagement** Establish more authentic opportunities for People with a Lived/Living Experience to participate in planning, delivery and evaluation of mental health, suicide prevention and alcohol and other drug treatment services.	• identify and share best practice ideas, case studies, resources and tools that support the system to undertake authentic engagement occurring at the needs assessment, design, delivery, review and evaluation stages of the commissioning cycle. • develop an online communications strategy to link a wider audience of People with a Lived/Living Experience and services to promote participation and co-design, information sharing, evaluation and networking opportunities

Shared Objectives	Actions
	• provide oversight and advice to the Plan's governance groups, ensuring that actions that relate to the engagement and involvement of People with a Lived/Living Experience are meaningful, genuine, authentic and embedded throughout implementation • identify, inform and gain feedback from People with a Lived/Living Experience and experiences with the National Disability Insurance Scheme (NDIS).
1.4 **Regional and Sustainable** Establish and sustain a consistent region-wide approach to participation by People with a Lived/Living Experience in mental health, suicide prevention and alcohol and other drug treatment services.	• review, research and continue to develop regional coordination • develop a clearinghouse of best practice resources on engagement of People with a Lived/Living Experience, Consumers, Carers and Families • sustain and strengthen existing peer participation and collaboration mechanisms through mentoring, supervision, peer reflection and self-care initiatives • review, share and utilise existing plans, research and guidelines from all levels of government and industry relevant to People with a Lived/Living Experience's role in service delivery and commissioning.
1.5 **Workforce Development** Advocate for an expanded and more diverse regional Lived/Living Experience workforce, across all levels of employment.	• promote and participate in local, regional, state and national research to better understand the existing profile of peer work emerging issues, commitment and culture • promote and contribute to national and state-wide initiatives aimed at building the Lived/Living Experience peer workforce, including the QLD framework for Lived Experience Workforce and National Guidelines for Peer Workforce • contribute towards broader workforce development strategies being developed at a national and state level, and use this to co-design and implement a local and regional response towards a Lived/Living Experience workforce • identify and promote a comprehensive range of workplace roles for People with a Lived/Living Experience in the mental health, suicide prevention and alcohol and other drug treatment services sectors • identify opportunities for peer workers to become service providers through the NDIS

Shared Objectives	Actions
	• identify and contribute to shaping organisational readiness that embeds people with Lived/Living Experience and supports good mental health and wellbeing in the workplace.

Recommendation 2

That the Shared Objectives and Actions in Chapter 2 of *Planning for Wellbeing*, detailed below, be adopted and coordinated at a state-wide level, with co-investment by PHNs.

Shared Objectives	Actions
2.1 Provide information, resources and skills building to support families and carers.	• all providers to promote the Carer Gateway and regional integrated carer support service to carers and families and ensure specific mental health carer advocacy, information and capacity building support is available for carers in relation to mental health, suicide prevention and alcohol and other drugs.
2.2 Better care for families and carers.	• review the generic carer pathway for carers and review inclusion of carer information and supports in HealthPathways portal every 12 months • encourage providers to nominate a named contact person for carers, such as a peer worker or carer liaison role • develop a platform for the promotion of services and supports providing income and employment support to carers, particularly in peer worker roles.
2.3 Families and Carers are listened to and involved in services.	• all providers to encourage the incorporation of approaches such as the Triangle of Care model where consumers, carers/families and providers work together as partners • Brisbane North PHN and Metro North HHS continue involvement with the Carer Gateway, to ensure it meets the needs of carers and families of people experiencing mental illness, suicide risk and people experiencing problems related to the use of alcohol and other drugs • review the full and effective involvement of carers in the NDIS, both at an individual and policy level • continue the involvement of carers and families in PHN and Metro North HHS service planning,

Shared Objectives	Actions
	delivery and governance structures and extend this approach to other providers.
2.4 Services are more responsive to the needs of People with a Lived/Living Experience and families and carers.	• providers commit to active engagement and participation in education and training on the perspectives of carers and on family-inclusive practice • ensure all health practitioners have the requisite qualifications for their role and are matched to the level of need of the service consumer, carers and families • facilitate improved access to mental health, suicide prevention and alcohol and other drug treatment services when and where service consumers need it, with providers sharing outcomes and learnings of improvements.
2.5 Services are more responsive to the needs of carers and families.	• strengthen consumer- and carer-centred practice, particularly at time of diagnosis, intake or admission to a service, by actively referring carers to support options. Services providing information for carers regarding participants' clinical or support information is done with the consent of the consumer. • strengthen the early involvement of carers in discharge and transition planning, working within privacy policies and procedures • providers commit to the incorporation of appropriate standards and approaches such as the six partnership standards for working with carers and to undertake any associated self-assessment processes.

For further information or comment please contact PPIMS via email [redacted]

PPIMS delegates would be interested and available to appear before the Committee.

Attachment 1

Submission to the INQUIRY INTO THE OPPORTUNITIES TO IMPROVE MENTAL HEALTH OUTCOMES FOR QUEENSLANDERS by Paul Justice, a PPIMS network member

Lived experience workforce

I found Peer Support can be very rewarding personally and give you much pride in being a person helping another person with lived experience and in a vulnerable position with mental distress and helping their family or carer with information with supports in the community. And sometimes [it is] very frustrating due to being a casual worker with under-employment and with on call changing shift work and working two different peer support roles in the HHS and also working for an NGO. As a peer support worker I offered support and encouragement when things didn't go according to plan, as well as reassurance and understanding that feelings of frustration and disappointment were common experiences. A peer support worker believes that the individual's abilities to build resilience and be persistent as well as learning to deal with frustration are important outcomes of these interactions in difficult situations. On many occasions as a peer support worker I would be appropriately sharing with an individual and sometimes their family or carer that I'd had similar experiences and how I had dealt with these and learnt strategies and accessed wellbeing supports to help me manage my mental health. Peer support workers believe that by sharing that they had similar experiences, a safe space (e.g., in a group setting) can be created to talk about sensitive topics. These interactions were described as allowing these individuals to develop new coping and social skills as well as becoming more adaptable when facing adversity. The role is not without challenges, including a lack of clarity around the role, causing confusion, and lack of role credibility. The peer support worker's emphasis on shared engagement in everyday experiences aligns with the importance of personal recovery concepts. Personal growth and living a meaningful good life may be viewed differently to measures of clinical effectiveness/emphasis on symptom reduction. Difficulties defining and maintaining peer roles can be complicated within clinical settings where tension between recovery and the medical model may be more pronounced.

Workplace Support, Supervision, Debriefing, Workplace Team Meetings

But there is a lack of support for peer support workers with vicarious trauma and compassion fatigue; also phone or face-to-face limit of 6 counselling sessions. And even if a peer support worker sustains a traumatic physical injury or psychological injury in their workplace [there is no support] – only there is some support through the Employment Assist Program (EAP). But the peer support worker must rely on their own medical team of GP, allied health services (Physio, Exercise physiology) and Psychologist and Psychiatrist.

Training

Qualifications for peer workers include: Certificate IV in Mental Health and Peer Work or a Diploma of Mental Health, Certificate IV or Diploma in Alcohol & Other Drugs, Mental Health First Aid, Suicide Prevention Training and trauma informed training.

Improvements in Training

Ongoing diversity and inclusion training for all staff is needed, as well as training in unconscious biases with social stereotypes about individuals with mental distress and mental health diagnosis in are communities. Peer workers can help facilitate this training with examples of their lived experience of experiencing discrimination from unconscious biases and how it causes stigma in are communities and self-stigma feeling to an individual or their family. To provide staff with the tools to adjust automatic patterns of judgmental thinking and discriminatory behaviours in the workplace and in the community.

Benefits

The benefits of being a peer worker include building personal strengths and core values. (Physical and mental health and wellbeing/social/economic)

Connection and Collaboration

Connection and collaboration built with peer support from a peer support worker can be a way that someone who may otherwise feel isolated gains a sense of personal connection, particularly because there might be a common experience and similarities shared between the peer support workers and the person with mental health distress and helping people navigate into appropriate mental health support services.

Validation and De-stigmatization

Stigma and unconscious biases with social stereotypes about individuals or groups in our communities and focusing on negative qualities of an individual's appearance, behaviours, and reasoning abilities is a stigmatizing experience especially among individuals having a mental health condition. If an individual feels alone and isolated from their family and friends and their community with the experience of mental health distress, it may prompt emotions of sadness and disenfranchising sense of identity, value and change in their behaviour. A peer support worker can help to counter these feelings and help an individual feel validated, respected, heard, and understood with their lived experience and can create a more diverse and inclusive environment. The peer support worker can share their own lived experience story and journey to inspire and encourage people to build self-efficacy knowledge to promote better choices for the individual's sense of health and wellbeing. It can also help an individual to feel a greater sense of awareness of worth and empowerment to make meaningful choices in managing their mental health.

Stigma and Normalization

Feelings of mental distress and disconnection and a loss of sense of social identity and isolation can prompt loneliness. Knowing that someone else has experienced similar feelings can help an individual to feel as though their experience is not abnormal, which can be both meaningful and assuring.

Purpose

Peer support workers and peer support groups can provide a sense of purpose both for the individual and their carers and for the peer support workers as they build rapport with people, and all learn from their shared knowledge and create a supported environment. The idea behind peer support is to listen to and reinforce a person in their individual lived experience. This can provide purpose to the work that the peer support worker is doing and help a person or group of people to recognize this individual's own purpose and personal values and individual strengths.

Hope

Mental health distress symptoms and disorders vary widely and may affect a person's mood, thinking and the ability to socially interact with family, friends, and peers in their community. Depression, anxiety, and other mental health disorders and persistent feelings of loss of connection and panic can be debilitating for people. During feelings emotional despair, it is not uncommon for an individual to lose hope. Peer support can be a lifeline of hope for someone who is struggling. A peer support worker opening up and sharing about their own personal story and challenges may be very comforting in the moment and allow the client to have trust and share their experience. That solace and connection can be a catalyst to bringing about or restoring hope for a person.

The peer support worker's emphasis on shared engagement in everyday experiences aligns with the importance of personal recovery concepts. Personal growth and living a good life may be viewed differently to measures of clinical effectiveness/emphasis on symptom reduction.

Challenges

There is no job security according to my experience as being a casual employee peer support worker and the general lack of permanent or part-time positions for peer support workers. And having to be on call for shifts, this does not support routine and structure for the daily lives of the peer support worker and has the side effect of the stress for peer support worker being under-employed in working hours for me to earn an income or having to work two casual position at different organizations with different policies and work requirements and shifts can be crossed being an on call casual employee for two different organizations. This can cause stress and fatigue and create concerns about following different policies and procedures and work routines with the requirements of your duties.

In my experience maintaining living/lived experience values and person-centred recovery practice skills can sometimes be difficult and defining and maintaining peer roles can be complicated within clinical settings and their requirements where tensions between recovery and the clinical medical model may be more pronounced and have a different outcome for individual wellbeing and recovery than with recovery-centred model. As a peer support worker, I viewed my role as dissimilar from the clinical staff and believed that the lived experience view facilitated learning and brought inclusiveness and a recovery-oriented environment. Clinicians can learn from the living/lived experience of peer support workers as advocates and voices for change within the team for social justice and inclusive practices.

Peer-Led Organisations

Peer-led organisations are leaders in the lived experience workforce fulfilling the needs of support services of people with living/lived experience of mental distress in the community – they are grassroots community organisations built by people who are passionate about the foundation of having the shared experience of working towards recovery from a mental health concern. This shared experience of recovering is what binds us together as a community. It allows for:

- building and maintaining authentic and mutual connections with peers
- being genuinely empathetic and non-judgmental

- sharing our hope, knowledge, and experience and showing that recovery is real and possible
- challenging ourselves and others to fully explore and engage in recovery
- sharing strategies that have worked for us
- challenging stigma and discrimination by openly demonstrating recovery and the skills and abilities that people who experience mental health challenges have

Examples of peer-led organisations in Queensland include: Brooke Red, Peach Tree Perinatal, Grow Australia, and many peer support groups and alcohol and other drugs peer support groups (e.g., Alcoholics Anonymous, Narcotics Anonymous Australia) and Disability Peer Support Groups such as the Queensland Disability Network.

There needs to be promotion and community engagement within communities with social justice and living/lived advocacy about the benefits and services peer support groups provide in are communities and regions throughout Queensland and a commitment to long-term funding and support for engagement with all levels of government (local councils, State and Federal)

Consumer and Carer Engagement

We need more diversity and inclusive living/lived experience leadership and social justice advocacy initiatives within the framework of engagement for when evaluating and implementing new and existing services to have better outcomes for people needing these supports and services, and for the consumer and carer experience to be at the forefront on implementing and building support services in our hospitals and mental health services in the community.

Service Gaps and Waiting Lists

We need appropriate services and supports for people who fall between the gaps in services – for example, are not eligible to get NDIS funding supports and are not getting Queensland Health HHS services and supports.

People need to be able to find the support services in their communities efficiently and, when services are found, without long waiting lists. I still see people waiting months to get the support services they need especially, and services need to emphasise their autonomy and provide person-centred directed care, and have belief in the person's inherent capacity and dignity of risk to manage their informed choice concerning their supports and health service needs.

No Wrong Door

People need to get support and medical help with a no wrong door approach whatever service they approach, in the right place and in a timely matter. And to not be told that support services you need are unavailable at the moment, and you could be put on a long waiting list for help or that services are not available in your community. We need to be responding in a timely matter before people deteriorate and the costs of their personal health and support care increases dramatically.

Services For All

We need a commitment to no longer see a lack of wrap-around supports at our hospitals and in our community support services, and consistent continuity of care for individuals in crisis of mental distress and their family/carers.

Social Justice and Community Health

The actual cost to health services increases when we don't respond appropriately with medical help and supports for the whole person and their families/carers all of their needs – and we see the government funding and community services spent in other areas. We need social justice and equality and empathy for people instead of the cost of having people go through traumatic situations when they are vulnerable and in distress, going through other systems such as police, courts, jails instead of getting the help they need and better social housing, having to rely on food parcels and being a loss economy in our communities because they lack basic help and support. We need to be realistic and that change needs to happen and to hold governments at all levels accountable to not responding adequately to

Governments need to recognise the true cost to the economy and communities when we do not provide and fund adequately health and support services and the real cost to families/carers that have such an important role in supporting the individual to manage their mental health and physical health. They need people with lived experience in all levels of the public service.

Mental Health Initiatives in the Workplace

Mental health initiatives in the workplace are needed to support people with mental health conditions and when facing distress or a crisis. We need better training and holistic supports with a lived experience-led approach within the framework of health and safety to include mental health to manage and improve a healthier and more supportive workplace. And lived experience promotion and consulting service programs that promote savings and benefits and employee retention to businesses and workplace performance when they support management and all employees with inclusive mental health supports.

Paul Justice

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