

# Same Same Different: Social change values in mental health peer support

## Research Proposal Summary

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## GLOSSARY

Lived Experience (capitalised)	Experiences of life-changing mental health challenges, service use and periods of healing which have profoundly impacted a person's worldview; direction; and changed life as they knew it. This can be a direct personal (consumer) experience or an experience as a family member/carer supporting a loved one facing mental health challenges. <sup>1</sup>
Lived Experience literature	Literature authored and controlled by people who identify writing from a Lived Experience perspective.
Lived Experience perspective	Contextualised understanding of personal Lived Experience in relation to the wider Lived Experience movement and universal issues of marginalisation and loss of identity/citizenship. <sup>2</sup>
Lived Experience workforce	People employed in identified Lived Experience roles to assist others by applying what they have learnt from their direct experience of mental health challenges, service use and recovery. <sup>3</sup>
Peer (capitalised)	A person with Lived Experience
Peer Support (capitalised)	Formal support offered by people who identify and use their Lived Experience to assist others
Psy-disciplines/Psy-services	Disciplines and services that constitute the bio-medical psychiatric service system.
Social change	Sustained changes in the status-quo social order of dominant patterns of social discourse and behaviours across groups, institutions, systems and communities.

<sup>1</sup> Louise Byrne et al., 'Queensland Framework for the Development of the Mental Health Lived Experience Workforce', *Queensland Government: Brisbane*, 2019.

<sup>2</sup> Louise Byrne et al. 2019.

<sup>3</sup> Louise Byrne et al., 2019.

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*This is our experience.... This is our understanding of it. We know there are more powerful and acceptable versions of what happened to us. Ours may not be heard. ... Telling it to other people is difficult ... We learn that people who have not been through it, may not always be able or want to believe us. Or it may be too painful for us to share such terrible things with others when we can expect that they may not be able to believe or understand us. But this is our account. This is what we have to say.*

(Beresford 2006, p.164)<sup>4</sup>

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## OVERVIEW

This study is a PhD project conducted through the Lived Experience Research Unit at the Australian National University (ANU). It will examine the role social change values play in shaping mental health Peer Support practices in diverse settings across Queensland. It aims to contribute a Queensland-specific, Lived Experience controlled (and practice-based) perspective to the academic literature defining mental health Peer Support practices.

People who use or are detained by psychiatric services often turn to each other for mutual (peer) support. Historically, peer support between those who found psychiatric treatments inadequate and/or harmful gave rise to a multi-vocal activist movement seeking to dismantle, reform, or improve psychiatric services. Activism by what has become known as the consumer/survivor/ex-patient movement facilitated the emergence of a Lived Experience / Peer Support workforce which has become the fastest growing workforce in the mental health sector. This emerging discipline is now under intense pressure to define and standardise its practices. Many Lived Experience leaders are adamant that defining our discipline and practices must be led (and decided) by those who have first-person, direct experience as Lived Experience / Peer Support practitioners. The *Queensland Framework for the Development of the Mental Health Lived Experience Workforce* (Byrne et al 2019: p10<sup>5</sup>) emphasises that formal Peer roles are informed by how Lived Experience is contextualised in relation to the wider consumer/survivor/ex-patient (c/s/x) activist movement, together with universal issues of marginalisation, and the loss of identity and citizenship rights. We contend that contextualise Peer practice in this way depends on a nuanced understanding of the history of psychocentrism; the consumer/survivor/ex-patient movement; diverse Lived Experience perspectives and social change values together with an understanding of how that is reflected differentially in current Peer Support approaches.

Mental health Lived Experience/Peer Support practices are grounded by a history of people who have been psychiatrised supporting each other; consciousness raising through sharing experiences; experientially learning together to create new knowledge; and challenging injustices in the systems that impact their personal lives. Hence this project has engaged local Peer Support practitioners as Associate Researchers to collectively drive the research within a community-based participatory research methodology. Research findings will inject the perspectives of Queensland-based Peer Support practitioners in local, national and international debates seeking to define mental health Peer Support

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<sup>4</sup> Peter Beresford, 'Making the Connections with Direct Experience: From the Western Front to User-controlled Research', *Educational Action Research* 14, no. 2 (1 June 2006): 161–69, <https://doi.org/10.1080/09650790600717987>.

<sup>5</sup> Byrne et al., 2019, 'Queensland Framework for the Development of the Mental Health Lived Experience Workforce'.

practices. Research findings will also contribute to developing training materials focused on values-driven practice for the local Lived Experience workforce.

## THESIS STATEMENT

We contend that understanding the nexus between social change values and Peer Support practice is pivotal to

- Distinguishing mental health Peer Support practice from other disciplines
- Differentiating between diverse Peer Support practice approaches
- Understanding how Queensland-based Peer Support practice approaches are contextualised in relation to the c/s/x activist movement

## RESEARCH QUESTIONS

With reference to adult mental health Peer Support practices across Queensland, this study asks

1. What role do social change values play in shaping Peer Support practices?
2. Which values are common across diverse practice approaches?
3. Which values distinguish between practice approaches?

## RESEARCH TEAM

### COORDINATING PRINCIPAL INVESTIGATOR

**Chérie McGregor** is responsible for initiating and leading this research project. She has worked (for over a decade) in identified Lived Experience roles in mental health treatment services; mainstream and peer operated community services; and academic institutions across Queensland.

### ASSOCIATE RESEARCHERS

**Amanda Waegeli** has worked in designated Lived Experience leadership roles in government and non-government organisations in Western Australia. Since moving to Queensland, she has worked independently as a national Lived Experience trainer, consultant, supervisor and systemic advocate.

**Brooke Starr** has over eight years' experience working as a Peer Support practitioner and systems change advocate in local, regional, and statewide positions.

**Helena Roenfeldt** is a Lived Experience researcher specialising in critical and alternative perspectives in mental health. Her personal experience continues to drive her work and fuel her desire for change.

**James Hill** is an award-winning advocate who pioneered the first Lived Experience mental health advocate roles at Energy Queensland in 2017. He is also a Mental Health First Aid instructor and Beyondblue speaker.

**Kev Stevenson** is a Peer Support practitioner, public speaker and consultant who shares his insights about critical incident stress. As a former firefighter, Kev pioneered the first Lived Experience speaker role with the Queensland Fire and Emergency Services.

**La Rue De Vries** is a proud Quandamooka woman who draws on her cultural knowledge and Lived Experience in providing Peer Support.

**Michael Burbank** has more than 20 years' experience in the mental health sector. He currently teaches the Certificate IV in Mental Health Peer Support.

**Michelle Sanders** has over twenty years' experience in both consumer and carer Peer Support roles. She currently works in a mental health service, champions Lived Experience workforce development, and is also an associate researcher on other research projects.

EXPERIENCE		Chérie	Amanda	Brooke	Helena	James	Kev	LaRue	Michael	Michelle	UNREPRESENTED	
Lived Experience	Direct (Consumer)	✓	✓	✓	✓	✓	✓	✓	✓	✓	Central, north and far west Queensland regional and remote areas	
	Support (Carer/family)	✓	✓		✓					✓	People working in identified carer-specific Lived Experience roles	
Communities	Metro		0	0	Brisbane					Gold Coast	Torres Strait Islander peoples	
	Regional	South East	South West	South East		South East	South East	South East	South East		Culturally and linguistically diverse peoples	
	Aboriginal							✓			Signing deaf people	
Lived Experience role by service delivery setting	Peer-Run	0	0	✓			0	0	✓		People who identify as members of the LGBTQIA+ community	
	Community-based	0	0	0					0		Young people	
	Hospital	0	0	0					0	✓		
	Industry					✓	✓					
	Private Business	✓	✓	0			✓					
	Academia	0	✓		✓				✓			
<b>LEGEND</b>												
											✓	Current Experience
											0	Past Experience

Table 1: Associate Researchers' collective experience

## COLLECTIVELY OWNED RESEARCH

All members of the Same Same Different research team contribute from pre-existing intellectual property. Individual contributions have significant impact on our collective decision-making that drives research design, data analysis and findings. This research would not be possible without the (unpaid) contributions of the Associate Researchers. As such, the only just and fair answer to the question 'who owns the intellectual property produced by this research?' is simply 'all members of the research team'. Consequently, a legally binding, intellectual property contract is in place detailing and solidifying this position.

## RESEARCH STRATEGY

### RESEARCH ACTIVITIES

#### Phase One - Online Survey

The online survey tool quantitatively captures broad contextual data and scopes practice values for the Lived Experience workforce across Queensland. It will be designed and administered online using Qualtrix. Paper-based versions will be available on request.

#### Phase Two - Interviews

Semi-structured interviews will be conducted to gain an in-depth understanding of the impact of social change values on mental health Peer Support practices in diverse service delivery settings across Queensland.

To register interest in participating in interviews, respondents will need to complete an expression of interest (EOI) process which includes completing the online survey (used in the first phase of this study). This is intended to enable a contingent purposeful sampling to best represent diversity across values positions, practice settings and geographic locations. De-identified survey results for potential interview participants will be reviewed by Associate Researchers involved in selecting interview participants. De-identified data from the EOI surveys will also be integrated with data collected through the interviews.

Interviews will be conducted out of business hours and digitally video-recorded online using Microsoft Teams. Transcripts will be provided to participants to review, with an option to elaborate on comments and/or request all or part of the transcript to be excluded from the data analysis. Transcripts will be identified or de-identified (according to participant preferences identified in consent forms) and analysed using constructivist grounded theory method. Only appropriately de-identified and participant approved data will be provided for consideration by the Associate Researchers.

### **Phase Three - Focus Group Discussion**

Focus group discussions will engage Lived Experience/Peer Support practitioners in critically reviewing the emerging findings. Access to online forums will be restricted using the 'by invitation' function in Microsoft Teams. Only Lived Experience / Peer Support practitioners who have returned signed, written consent forms will be provided with the log-in details for the online focus group discussions.

### **Phase Four - Literature review**

Consistent with common practice in applying a constructivist grounded theory methodology, this study will undertake a literature review *after* the substantive theory has been well developed and examined through focus group discussion. This not only serves to avoid distracting attention away from the empirical data, but also ensures that researchers are positioned to integrate the research findings with literature current at the time of publication.

## **ETHICAL CLEARANCE**

This project has received ethical clearance from the Gold Coast Health Human Research Ethics Committee (HREC/2021/QGC/74459) and recognised by the ANU Human Research Ethics Committee. Academic and ethical reviews will be completed according to schedules required by the approving Human Research Ethics Committees and ANU to ensure the study complies with relevant legislation and standards.

## **RESEARCH GOVERNANCE**

This study will be conducted as an ANU PhD project, under the supervision of Associate Professor Michelle Banfield (primary supervisor), Dr Louise Byrne, Ms Suzi Quixley, and Dr Bianca Calabria.

## **PARTICIPANT ELIGIBILITY, RECRUITMENT AND COMMITMENT**

Participants recruited for this study will be over 18 years of age and currently working in (paid or volunteer) identified Lived Experience / Peer Support roles in diverse practice settings and locations across Queensland. In consenting to be involved, participants will nominate whether they want to participate anonymously or be identified and acknowledged for their contributions.

## RISKS AND BENEFITS OF PARTICIPATING

The primary benefit of participating in this study is potential self-satisfaction in contributing to research that injects Queensland/practice-based Lived Experience perspectives in academic literature defining mental health Peer Support practices and training materials for the workforce. This study is focused on professional practice and does not seek to examine personal Lived Experience backgrounds or evaluate practice efficacy. As such, the potential for involvement to cause distress for participants is minimal. Any data collected that may be perceived as critical of workplace settings will be de-identified so that the participant and workplace cannot be recognised.

## DISSEMINATION OF RESEARCH FINDINGS

Research findings for this study will be disseminated through

- Publishing in
  - I. Academically peer-reviewed journals
  - II. Open source creative commons
  - III. Non-academic platforms including Lived Experience controlled websites
- Presentations through Lived Experience workforce networks and conferences
- Training materials for Peer Support practitioners

## SIGNIFICANCE

Research findings aim to contribute to the ongoing development of a Lived Experience controlled, practice-based, body of knowledge defining mental health Peer Support practice approaches within an Australian context.

This research aims to provide a lens through which to consider

1. The ways in which Queensland-based Peer Support practices contextualised Lived Experience in relation to the wider c/s/x movement
2. The extent to which existing mental health Peer Support practices across diverse settings are (or are not) committed to a dual focus on mutual support and social change
3. The extent to which research and commentary by psy-professionals influences how mental health Peer Support practice is described, understood and defined.

It is anticipated that this research will contribute to vocational training for Peer Support to build workforce capacity for

1. Identifying how direct, first-person experiences of contact with mental health services informs social diverse social change values in the c/s/x civil rights movement
2. Articulating the interconnection between the c/s/x movement and mental health Peer Support practices
3. Identifying and navigating values-driven conflict within workplaces, the Lived Experience workforce, and the broader activist movement
4. Identifying the complexities of being a social change agent positioned within systems that actively seek to maintain the current status quo of how psychiatry defines and responds to experiences of distress and madness



## LIMITATIONS

The scope of this study is limited to adult mental health Peer Support services in Queensland. This excludes mental health Peer Support services provided by people under the age of 18 and Peer Support that is specifically focused on challenges associated with the use of alcohol or other drugs. The current membership of the Associate Researchers Team does not include representation of some key stakeholder groups including Torres Strait Islander peoples; people working in identified carer Peer Support roles; young people; signing deaf people; people who identify with the LGBTIQ+ community; and people living in remote far north or western Queensland communities. Together with a small sample size, this may limit the perceived scalability of research findings. The limitations of sample size is mitigated to some extent by including a quantitative, sector wide survey and applying constructivist grounded theory methods to maximise the transferability of results.