Summary

In response to the frequent criticism aimed at peer/lived experience research – that it is not robust enough, I have spent the past nine years building a program of research which includes four separate research studies. Each project has built from, tested and further investigated the findings of the last. My PhD explored the perspectives of people in a vast range of lived experience roles and settings across Australia. Key findings from this study indicated the need to better understand the perspectives of executive and senior management of mental health organisations, due to their potential role in championing and setting the cultural tone for lived experience inclusion. This second study reinforced the findings of the PhD in relation to supportive factors and barriers, and showed clear delineation between those with significant experience employing lived experience roles and those with little or no experience. Findings from this research demonstrated the correlation between exposure to lived experience roles, understanding and perceived value of the roles, and commitment and action in supporting the roles. Simply, the more exposure management participants had, the higher their understanding, perceived value and active commitment to lived experience workforce development. This project also highlighted the need for whole-of-workforce buy-in. So while it was confirmed that management championing of lived experience is essential for acceptance in the workforce, understanding and championing at all levels of the organisation was also needed.

Following the initial studies in Australia, I was successful in achieving a Fulbright Postdoctoral Scholarship to test my findings in the United States. The Fulbright research provided an opportunity to include a whole-of-workforce focus. This was accomplished by seeking participation from people in 'traditional' management roles, designated lived experience management roles, mental health professionals, corporate staff including H.R. and administrators, as well as lived experience workers. It was also an opportunity to take further the findings of the previous studies and explore in more depth and from a greater variety of perspectives, issues around supportive factors and barriers, perceived value of lived experience, credibility of the roles, uniqueness of the roles and cultural diversity within the lived experience workforce.

A total of 132 people participated in this qualitative study including: 47 in management positions (not peer designated), 7 designated lived experience management positions, 32 licensed mental health professionals, 38 designated lived experience positions (not management), 8 ‘other’ including H.R., administrative roles and ‘carer’ roles.

Focus

Meaningful inclusion of lived experience perspectives is increasingly considered an important factor in best practice mental health service delivery. However, it is still emerging and often poorly understood. Consequently, how to embed lived experience workers within a multi-disciplinary environment is poorly understood, resulting in significant challenges for lived experience workers. These challenges include lived experience workers being stigmatised, professionally excluded, employed in tokenistic positions, and asked to perform functions that are not appropriate/authentic to their roles.

To better understand what aids the effective employment of lived experience roles, the Fulbright research focused on five organisations that were identified as demonstrating ‘best practice’. Organisations were identified by an advisory group of 12 lived experience experts and allies from across the United States. Advisory group members helped to define ‘effective’ employment and nominated organisations they felt demonstrated commitment to best practice in the employment of lived experience roles. Within these organisations lived
experience workers were established members of the multi-disciplinary team, all organisations had lived experience designated roles in middle and/or upper management and all organisations had demonstrated ongoing philosophical and financial commitment to the development of their lived experience workforce.

**Potential Impact**

While the Fulbright research focused on best practice, this is still an emerging workforce and many barriers remain even in many ‘best practice’ settings. Findings of this research provide valuable insights about the risk of co-option, inclusion of diverse cultures, defining the ‘lived experience’ necessary, and the unique features and functions of lived experience roles.

While conducting this research I was based at Yale in the ‘Program for Recovery and Community Health’ (PRCH) led by Professor Larry Davidson. Professor Davidson has researched lived experience roles for over 25 years, as an important outcome of his work, PRCH developed a toolkit to aid the integration of lived experience workers in mental health settings. My Fulbright findings will be used to revise and develop this toolkit further.

In the Australian context, findings from all three studies provide the core data to inform the ‘Queensland Framework for the development of the Mental Health Lived Experience Workforce’, which is expected to inform future development of the lived experience workforce, improving lived experience integration within mental health settings in Queensland.

More broadly, this study provides new directions and insights on creating a more culturally inclusive lived experience workforce which is relevant to International contexts.

**Consumers’ Contribution**

I am a person with a living experience of mental health challenges and have worked specifically from this perspective for 15 years. The thing I am proudest of in my career is managing to achieve what I have with ongoing, and at times significant difficulties with my mental health. Research is highly competitive and a demanding field, I have at times felt stigmatised and not been taken seriously due to my lived experience and working in an emerging field. However, I feel satisfied I have achieved to a high standard despite and sometimes because of, my challenges. I have devoted my career to assisting others like me to be better understood, valued and supported and I believe my contribution has and will continue to make a difference.

I also employ lived experience researchers on all my funded projects. In the current Framework for Queensland, the strategic forum (who have veto) are majority lived experience leaders, the advisory group is all lived experience leaders, focus groups will be conducted by local lived experience leaders, and we have gained input from specialised lived experience representatives identifying as Aboriginal and Torres Strait Islander, Culturally and Linguistically diverse and LGBTQIA.
Curriculum Vitae

Education
2010 - 2014 Central Queensland University  PhD *conferral date, March 10, 2014*
1998 - 1999 Griffith University  Master of Arts (with honours) in Media Production

*Career disruptions – during 2014-2016 I took a total of six weeks ‘carer’s leave’ to look after my elderly dogs. In recognition that I have no children or other dependents, my then employer allowed me to use carer’s leave to twice drive 600km for specialist treatment and care for my dogs when they had cancer. Then, when my little boy received a terminal diagnosis, I took the final three weeks of his life to nurse and spend time with him.

Academic Appointments:

06/2018 – 10/2018 School of Medicine, Yale University, New Haven, CT, United States: Visiting Research Scientist
08/2017 – 08/2020 School of Management, RMIT University, Melbourne, VIC, Australia: Vice Chancellor’s Postdoctoral Fellow, RMIT Postdoctoral Fulbright Fellow
03/2010 – 08/2017 School of Nursing, Central Queensland University, Rockhampton, QLD, Australia: Lecturer in Lived Experience Mental Health

Career Summary

Dr Louise Byrne is a researcher with deep knowledge of organisational issues relevant to ‘lived experience’ mental health employment. Louise’s work is informed by her own experiences of mental health diagnosis, service use and periods of healing. Louise has worked in a variety of designated lived experience positions across the mental health and higher education sectors since 2004, including the first full-time lived experience mental health academic role in Australia, and as an expert advisory role to the Queensland Mental Health Commission in 2015.

Louise is currently employed in the School of Management at RMIT University. In 2017 Louise was awarded the inaugural RMIT Fulbright Fellowship, which includes a 2017-2018 Fulbright Postdoctoral Scholarship and a three year Vice Chancellor’s Postdoctoral Fellowship at RMIT.

As the major component of her Fulbright Postdoctoral Scholarship, Louise conducted research on lived experience employment in the United States. During her Fulbright research, Louise was a visiting scholar within the Yale Program for Recovery and Community Health.

Louise has been a Chief Investigator on past and present projects that combined have been awarded over $1.3 million in competitive funding and has 30 peer-reviewed journal publications, several book chapters and numerous industry publications.

Media and Public Presence

In recognition of her work in this area, Louise has received several industry and academic awards and been featured on respected national media, including Radio National ‘Life Matters’, and as a panel member on ABC television’s Q&A https://youtu.be/DVm0fgELQuw

In 2017 Louise was nominated for a TEDx, in which she shared some of her personal journey and professional learning as a lived experience researcher https://youtu.be/01rwdqqaE4q
Louise has been an invited speaker or keynote at eleven regional, eight national and four international conferences/events. Most recently, Louise has been invited to present a keynote address at the 2019 TheMHS conference.

Community Engagement and Impact of Research

Louise’s work has focused on strong community engagement and has already demonstrated significant impact. Following her PhD findings, Louise was funded by the Queensland Mental Health Commission to conduct the research project, “Identifying barriers to change: The lived experience worker as a valued member of the mental health team”. In October 2017 the report for the “Identifying barriers to change” research was disseminated by the Queensland Mental Health Commission. In addition to the research report, the Queensland Mental Health Commissioner provided a two-page summary recommending the research to industry and highlighting key findings.

In November 2017 a group of lived experience leaders from across Queensland organised a one-day workshop to discuss Louise’s research findings and consider implications for workforce development. Following this event, the lived experience leadership group provided a position paper to the Queensland Mental Health Commissioner outlining the recommendations they felt should be prioritised. The Queensland Mental Health Commission then called for a meeting with the lived experience leaders, first asking whether it would be appropriate to include Louise ‘as a leading academic in this area’. Louise was invited and as a result of that meeting, Louise was funded to create the ‘Queensland Framework for the development of the Mental Health Lived Experience Workforce’. To inform the Framework, Louise is utilising her previous qualitative studies, including her Fulbright research in the United States. In addition to the qualitative data, as part of this research project, a quantitative survey will test the generalisability of the qualitative findings. The quantitative survey seeks input from a range of stakeholders including people employed in lived experience roles, ‘lived experience’ managers, traditional management roles, mental health professionals and corporate staff of mental health services. Members of the steering committee and advisory group for the project come from key organisations across Queensland including the Mental Health Alcohol and Other Drugs Branch - Clinical Excellence Division (Queensland Health), the PHN (primary health network) and various government and non-government organisations.

It is expected the Framework will provide a guiding document for widespread use in the public, non-government and private sectors to inform development of their peer/lived experience workforces and improve lived experience integration within state mental health settings. Ultimately contributing to more effective services and better outcomes for service users.

Previously Louise has been invited by the National Mental Health Commission as a ‘leader in this space’ to attend roundtable consults to guide the development of the Fifth National Mental Health and Suicide Prevention Implementation Plan, and development of national Peer Workforce Development Guidelines. Louise also authored a chapter of the seminal ‘Peer Work in Australia: A new future for Mental Health’ which was launched at Parliament House by the Minister for Health last September.

Journal Articles


5. Byrne, L., Roper, C., Happell, B., & Reid-Searl, K. The stigma of identifying as having a lived experience runs before me: Challenges for lived experience roles. *Journal of Mental Health* (Early View) 10.1080/09638237.2016.1244715


**Selected Recent Grants:**


Byrne, L. (2016). Identifying barriers to change: the lived experience worker as a valued member of the mental health team. Queensland Mental Health Commission $53, 283
Lived experience mental health

Thursday 24 March 2016 02:18AM (view full episode)

Louise Byrne is using her personal experience of severe mental illness to teach mental health nurses about the benefits of peer support. Informed by their own lived experience, peer support workers help patients navigate the mental health system and offer care and friendship on the road to recovery.
The Global Need for Lived Experience

Anthony Stratford, an INNOS board member from Mind Freedom, Australia recently co-authored an article published in the Psychiatric Rehabilitation Journal.

Co-authors are Louise Byrne from Central Queensland University and Larry Davidson from Yale University. The article spoke to the fact that leadership positions for persons with lived experience are lacking and that these positions are critical roles that will impact social policy, systems management, planning, education, program development and evaluation. The authors conclude:

“For true system transformation to occur, we argue it is essential for more attention and resources to be allocated to cultivating leadership skills among persons with lived experience of recovery and for opportunities to be created for such individuals to take on senior-level leadership positions within their respective countries and communities.”