How Much 'Lived Experience' is Enough?

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What kind and how much lived experience is required for Lived Experience work? Are designated roles necessary?

Take Home Messages

- Management had difficulty describing their understanding of 'lived experience' required for designated Lived Experience roles.
- Disagreement between managers about the need for designated roles and uncertainty in what lived experience is needed.
- Uncertainty by managers may impact whether or not they decide to employ Lived Experience workers.
- Need to increase manager's understanding regarding lived experience roles, otherwise lived experience roles may be co-opted.

Aim

To explore managers understanding of the lived experience required for

designing lived experience or peer roles within mental health.

Background

Previous research has shown that the role of management is important in supporting the effective employment of lived experience workers.

Evidence shows that lived experience workers are at least as effective as traditional mental health workers in supporting consumers. It also shows that lived experience workers have unique benefits in building community connections, promoting hope, increasing self-management and supporting personal recovery.

Lived experience workers draw on expertise gained through their experience to offer a unique perspective and specialised skills in their work. Historically lived experience workers were positioned as ‘outside’ the mainstream mental health system. But more and more, the inclusion of people with lived experience is seen as best practice within mental health service delivery and lived experience workers are considered essential in making organisations more recovery-oriented.

Greater inclusion within service delivery provides new opportunities and challenges for lived experience workers and service providers.

Some key challenges include:

- Key concepts of recovery (personal choice and self-direction) clash with the traditional medical model approach (focused on pathology and

allowing for involuntary treatment).
- Potential for co-option (assimilation of unique lived experience approaches into traditional service practices) of lived experience roles.
- Lived Experience positions can be questioned as contributing to stigma and reinforcing a person's identification with their experience of diagnosis and service use.
- Risk of 'othering' and discrimination of the lived experience workforce.
- Uncertainty regarding who qualifies as having relevant lived experience.
- Uncertainty regarding whether the lived experience that is required changes within different contexts (e.g. community vs. in-patient settings).
- Questions regarding how to define, and measure lived experience.
- A lack of role clarity for lived experience roles.

Method

This study involved interviews and a focus group with 29 participants from diverse management roles in not-for-profit, public sector and the community sector in Queensland Australia. The information and opinions given by participants were then analysed for common understandings.

Results

Themes from the interviews were:

What is the 'lived experience' required for lived experience roles

What level of recovery is needed?

Questioning the need for designated roles

Participant Quotes for: ‘What is the lived experience required for Lived Experience roles’ and ‘What level of recovery is needed?’

Quote 1

“I think you have to be really well, as the peer support [lived experience] worker, really well healed in your recovery journey and what I suspect has been the problem is people thought they were far enough along their own recovery journey to do this work. But once you get into the role and you’re kind of reminded of what you’ve been through and you probably have all sorts of triggers throughout the course of the work.”

Quote 2

“I don’t think it’s actually about a level of recovered or this idea that recovery is linear and that it somehow maps to your ability to do work”

Quote 3

“…who can determine what’s ‘recovered enough’ and what isn’t? I mean a lot

of people are in recovery and they have relapse, so relapse's a normal part oflife, so we all have ups and downs. But you know just saying 'you're not recovered enough to do this job' is a load of bullshit"

Quote 4

"Does it mean you have to have used a public mental health service, does it mean you just have to have had a diagnosable mental health condition, does it mean you could've had 6 or 12 months of really struggling, what actually qualifies you for having lived experience?"

Participant Quotes Relating to the Theme of Questioning the Need for Designated Roles:

Quote 1

"It's really valuable to employ people with a range of lived experiences, with a lived experience of mental health challenge and other lived experiences as well, other challenges. In our workplace here we encourage what we'd call human work, so we want our workers to be humans... rather than go down that road of having demarcated lived experience roles."

Quote 2

"I think every person in the world has a lived experience and a lived experience might be growing up and being a mum and a dad, your lived

experience mightn't contain a 'mental health issue' but you've still got a lived experience."

Quote 3

"… there's really something about challenging stigma that is about getting out there and that really changes perspectives, from the people who we provide support to, to ourselves, to our co-workers, to society at large, that you just can't achieve in the same way if you haven't been there and you're not wearing that [lived experience] tag."

Quote 4

"I definitely have personal experiences of feeling like I started to look like I'd been co-opted or wondering if I should start doing it like everybody else."

Discussion

The views of managers are important due to managers influence and decision-making role relating to the lived experience workforce.

Findings revealed inconsistent views about how much lived experience someone needed and how recovered someone needed to be to be an effective lived experience worker.

Some managers are resistant to employing designated lived experience roles because they do not understand how to define lived experience and are fearful of potential stigma associated with designated roles.

Some managers acknowledged the stigma and suggested the most effective way to challenge it is by having lived experience workers. They stated there was a need for lived experience workers to challenge stigma by publicly identifying with their experience of diagnosis and system use.

Some managers highlighted difficulty in expressing the uniqueness of lived experience roles, reflecting poor role clarity.

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