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PERSPECTIVE

Clinical Ceiling: Barriers to Lived Experience-Led Approaches in the Mental Health Sector

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ABSTRACT

Lived experience leadership is essential for reforming the mental health sector. However, deep-rooted barriers, such as entrenched mindsets and existing power structures, block the potential for lived experience perspectives to be leveraged for change. The aim of this paper is to critically examine the dominance of hierarchies that continue to marginalise lived experience roles and impede the advancement and authority of these roles in leadership and lived experience-led approaches. It emphasises the need to challenge systemic clinical authority and disrupt the prevailing dominance of the medical model in order to fully harness lived expertise, driving reforms and the creation of non-clinical alternatives.

1 | Introduction and Background

The mental health sector in Australia is undergoing a complex transition as awareness grows regarding its inadequacies in addressing the needs of individuals experiencing distress. There is also increasing recognition of the harms and prevalence of human rights violations within clinical settings (Katterl and Maylea 2021; Roennfeldt, Hill, et al. 2024). Current challenges are compounded by a range of factors, including rising levels of distress within the community (Enticott et al. 2022), and growing dissatisfaction with and recognition of the failings of the psychiatrisation of distress and limited explanations within a narrow illness model (Beeker 2022; Roennfeldt, Hamilton, et al. 2024). Psychiatric explanations serve to discount distress as a legitimate response to trauma and do not adequately reflect the contribution of intersectional disadvantage (Aas et al. 2023; Kirkbride et al. 2024; Mauritz et al. 2013). Psychiatrisation ultimately suppresses personal narratives and lived experience knowledge in the form of epistemic injustice (Fricker 2007). This is also indirectly (and sometimes directly) dismissive of other forms of knowledge and wisdom, such as those of First Nations, multicultural and queer communities (Mills 2014).

The dominant biomedical model, which informs the structure and approach of the mental health system, focuses on assessing and containing risk, which has led to a system that often, in times of crisis, responds with medication, seclusion, and restrictive practices, which can see people locked in hospital wards against their will (Minkowitz 2021). This is largely ineffective and harmful (Hughes et al. 2009; Jones et al. 2021). Critiques of the biomedical model within psychiatry highlight the lack of evidence and the reductionism of the complexity of life experience, such as the impact of trauma and oppression (Rocca and Anjum 2020).

Inappropriate and harmful responses within mental health systems have repeatedly been found to fail those for whom they were designed, breaching human rights and negating lived experiences (Katterl and Maylea 2021). Following the Royal Commission into Victoria's mental health services, Commission

chair Penny Armytage concluded that the State's mental health system had 'catastrophically failed' (https://www.abc.net.au/news/2021-03-02/victorian-mental-health-royal-commission-final-report/13203938). These ideas are not new. Similar conclusions have been made since the first inquiry into mental health services in Australia with the Burdekin Report in 1993 (https://humanrights.gov.au/our-work/publications/report-national-inquiry-human-rights-people-mental-illness). Ongoing systemic failings call for alternative approaches. However, despite the increasing recognition of the limitations and failings of current clinical approaches, they continue to be where almost all mental health funding is directed, expertise is sought, and decision-making authority is held (Patel et al. 2023; Rosenberg and Roberts 2021).

Through decades of advocacy, we see the development of lived experience-led approaches to service design, development, and delivery (Sunkel and Sartor 2022). Lived experience approaches are informed by a body of knowledge and skills founded on the expertise of survival, resilience, and resistance (Moore-Ponce 2025). They are approaches grounded in human rights, social justice, and ways of working that centre on relationship and connection (Mead et al. 2001). Lived experience approaches consider the role of oppression and social context, understanding that what someone is experiencing may be their brain, body, heart, and soul's best way of protecting them from trauma.

Lived experience-led approaches are advocated as viable alternatives to clinical approaches based on extensive evidence that they are fundamental to an inclusive, compassionate, and humane mental health and well-being system (Hodges et al. 2023). However, differences in the perceptions of clinical expertise and lived expertise in mental health services limit the potential for lived experience-led approaches to provide critical alternatives to the current system.

Progress has been made in the growth of the lived experience workforce in Australia, backed by policy imperatives that state mental health services should be informed by lived experience knowledge in the form of a designated lived experience workforce (Byrne, Wang, et al. 2021; Loughhead et al. 2020). However, the workforce is too often concentrated in peer support roles and remains under-represented in senior management and leadership roles (Sunkel and Sartor 2022). This is despite calls for greater lived experience leadership (Byrne et al. 2018; Byrne and Wykes 2020).

Barriers to lived experience leadership are well documented, including power dynamics in health settings, a misunderstanding of lived experience roles, a lack of commitment, and challenges in change management (Byrne, Roennfeldt, and O'Shea 2017). These challenges highlight the need for cultural shifts, resourcing, and accountability to ensure lived experience has authority at governance levels (Loughhead et al. 2024). The lack of people with lived experience in leadership roles and corresponding limitations of lived experience-led approaches reflect the ingrained power structures within the mental health sector and wider structural discrimination and paternalistic attitudes that persist for people with a diagnosis of mental illness (Voldby et al. 2022). The prevailing attitude is that clinicians have ultimate expertise and control over people accessing services (DuBrul 2014). Hierarchical divisions between clinicians and people with lived experience limit the potential and growth of lived experience-informed practice, leadership, and governance to shape the mental health systems of the future (Byrne, Roennfeldt, et al. 2021).

While the biomedical model and its proponents are the holders of power and the system enabling it, these structural problems risk the ongoing tokenism and invalidation of lived experience approaches, whether intentionally or not. More broadly, these negative perceptions mirror paradigms and structures built into our society that serve to devalue lived experience knowledge and reflect a value base and practices that shape and reinforce biomedical models. The prevalence of these biomedical paradigms reveals the risks of lived experience approaches being diluted or co-opted within dominant biomedical systems (Carr 2021). This paper considers the concept of the clinical ceiling in framing barriers to lived experience-led approaches and offers recommendations for concrete improvements to address these barriers and develop true alternatives to clinical services.

In discussing the dilemmas of lived experience leadership, it is fitting that the authors are all in designated lived experience leadership roles, bringing first-person accounts of the barriers to lived experience leadership. This insider perspective entails familiarity with practices and structures that devalue lived experience knowledge and perpetuate mainstream approaches and thinking. Consequently, this commentary offers a counterpoint to the tokenistic inclusion of people with lived experience, symbolising the need to push boundaries and embrace more progressive approaches to lived experience authorship.

2 | Introducing the Concept of Clinical Ceiling

From our examination of the limited opportunities for lived experience leadership and lived experience-led approaches in Australia, it is evident that a 'clinical ceiling' exists. The term 'clinical ceiling' was coined to refer to the ubiquitous need for clinical governance frameworks within mental health settings and the privileging of biomedical paradigms.

The metaphor of the 'glass ceiling' describes attitudinal or organizational bias and prevents women from advancing upward in organizations, and the subsequent vertical sex segregation (Powell and Butterfield 1994). Similarly, 'the clinical ceiling' illustrates restrictions on the influence of lived experience approaches through restrictions on people with lived experience in senior roles and resulting constraints in the principles and approaches of lived experience-led services. Few lived experience leadership roles exist in Australia, and these roles are often not given high-level decision-making responsibility or authority within a minimal scope of practice. Instead of discrimination based on sex, there is discrimination based on the deeply embedded ontological authority given to clinicians because of the perceived 'truth' and expertise of biomedical perspectives. These perspectives question and invalidate lived experience approaches and leadership. Furthermore, a lack of understanding of the expertise required for lived experience work also risks a watered-down version of 'lived experience' in leadership roles, where individuals in non-designated roles sidestep into

leadership positions without the necessary skills and foundational knowledge core to the lived experience discipline.

Under the clinical ceiling, lived experience-led approaches can only influence so far because they counter the hegemonic clinical practice models and ideologies focused narrowly on a medical model of diagnosis, symptom management, and treatment. This tension between lived experience, practice, and the medical model has been previously documented and described as two worlds colliding (Byrne et al. 2016). Consequently, the medical model perpetuates a deficit approach and low expectations for people based on a limited prognosis for recovery and a focus on biological causes rather than on what has happened to people. This story is repeated in developing non-clinical alternatives despite alternatives to hospital and emergency departments (ED) being meant to offer non-clinical options. Attitudinal and structural barriers impede lived experience-led approaches in these settings, highlighted in the expressed and overarching need for clinical governance, which maintains the status quo and systemic power within traditional models of mental health service delivery (Carr 2021). In practice, this means the clinical ceiling reinforces the clinical practitioner as the expert and, too often, decision-maker for other people's lives. Under the clinical ceiling, lived experience approaches are limited in how much they can influence reform and systemic change as they are invalidated within the context of the conditions and power structures in which they are applied.

3 | The Way Forward

The evidence is clear that to grow and adopt lived experience-led approaches, we need to redistribute power to lived experience leadership and models of practice from the existing hierarchies (Byrne et al. 2018; Daya et al. 2020). Lived experience-led reforms include:

- Developing a lived experience discipline comprised of values and practices that have the capacity for collective reform (Byrne, Wang, et al. 2021)
- Developing models for lived experience governance that provide pathways and opportunities to reshape service design and delivery (Hodges et al. 2023)
- Developing relational and dialogical approaches that influence all of our understandings, conversations, and relationships to achieve social change (Mead 2003).

Further, lived experience-led approaches have evolved to challenge and transform how we understand, conceptualise, and respond to distress in our society (Emejulu and Shaw 2010). The following examples from the advocacy and transformation work at Mind Australia (2024) articulate the potential for lived experience-led approaches in radically transforming how we conceptualise and respond to distress:

- Locate distress and experiences labelled as mental illness as interconnected with the sociocultural and political experiences of our lives, acknowledging the role of racism, discrimination, marginalisation, trauma and the ongoing impacts of colonisation and systemic violence.
- Radically disrupt and repair the impacts of a broken mental health system that is culturally unsafe, too often coercive, and dominated by biomedical approaches that locate the source of the problem within the individual.
- Offer ways of working with and alongside people in their worst and hardest times, grounded in love, compassion, and connection. Hold space for them to trust themselves and understand their experiences.

Ultimately, lived experience-led approaches, which are both radical and profoundly human, with collective courage, can transform our community's response to mental health (Sartor 2023).

4 | Relevance for Clinical Services

Beyond lived experience, we need an overarching human rights lens applied to all areas of mental health service provision to promote and protect people's rights and reduce harm within systems. Sweeping reforms and long-term strategies, including investment and restructuring, are needed to offer pathways to ensure people with lived experience can hold positions of authority and contribute to, and where appropriate, lead the reform of the mental health sector.

These reforms challenge hierarchical divisions and refuse to adopt coercive, punitive, risk-averse approaches to 'care'. Instead, they hold to the core values of lived experience approaches—mutuality and shared power. Therefore, these changes and the approaches they bring create tension and resistance from existing biomedical approaches (Carr 2021). Evidence indicates that resolving this tension requires changes at policy and governance levels, along with concrete actions and commitments from executive leaders and investments in career pathways for the lived experience workforce (Loughhead et al. 2021).

Lived experience leaders continue fighting for recognition and a valued position for lived experience-led services within the mental health sector. Nurses have made notable contributions in the evolution of the Consumer Movement, and ongoing advocacy from mental health nurses and other clinicians can challenge medical dominance while supporting systemic empowerment that elevates lived experience leadership (Byrne, Happell, and Reid-Searl 2017; Happell and Scholz 2018). By influencing resource allocation, valuing the experiential knowledge and expertise of lived experience leaders, listening without defensiveness to criticism of the current system, and driving the implementation of policies that increase the philosophical basis for alternatives, nurses can effectively support and facilitate lived experience leadership (Scholz et al. 2019). Addressing systemic barriers and valuing lived experience work will help to establish lived experience-led services as respected support options.

5 | Conclusion

Lived experience-led approaches offer a viable alternative. However, implementing lived experience-led approaches requires radical system transformation and investment in lived experience leadership. It will require the courage to take risks,

challenge longstanding power hierarchies, move beyond biomedical framing and its associated responses, centre intersectionality, human rights, and justice, trust in the voices of those who have lived experience, and demonstrate courage to step into new ways of being and doing. To date, attitudinal and structural barriers and a lack of political will have stood in the way. To maximise the potential of lived experience work, we must enable lived experience-led practices and leadership, smashing through the clinical ceiling.

Author Contributions

Katie Larsen developed the initial concept and wrote the first draft. Helena Roennfeldt led the writing and revision of the final paper; Debra Carlon and Ellie Hodges contributed to the revision, and Louise Byrne contributed to the initial ideas.

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Disclosure

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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