



Why lived experience matters

Introduction

The term *lived experience* has become central to discussions about disability, mental health, addiction, social care and policy development. Organisations increasingly seek to include people with lived experience in service design, governance, consultation, workforce development, and research. This reflects an important recognition that people directly affected by policies and services hold knowledge that professionals alone cannot provide (Bellamy et al., 2017; Wellcome, 2025).

As organisations attempt to move beyond consultation towards meaningful co-production and shared decision-making, some questions have become increasingly important: is lived experience a method of challenging systems and creating social change? Is it a workforce role, a form of expertise, or personal experience? Alongside the growing recognition of lived experience, there is therefore increasing debate about what the term means. (Clifton et al., 2025).

This article explores how lived experience is understood today, examines current debates about lived experience and expertise, identifies examples of good practice, discusses common challenges and offers recommendations for meaningful inclusion.

What Do We Mean by Lived Experience?

At its simplest, lived experience refers to knowledge gained through direct personal experience. This may include living with disability, mental health issues, substance use challenges, homelessness, poverty, trauma, discrimination, institutional care, or other significant life experiences.

Traditionally, organisations have viewed lived experience primarily as personal perspective or testimony. People are invited to share their stories so that services can better understand the realities faced by those they support. These stories can challenge stereotypes, reduce stigma, and provide valuable insights into how systems are experienced by those who use them (Repper & Carter, 2011).



In recent years lived experience became more than storytelling. People who spend years navigating health, welfare, education, housing, or justice systems often develop deep practical knowledge about how those systems work, where barriers exist, and what changes are needed. This knowledge is often unavailable to professionals who see systems from the inside rather than from the perspective of those receiving support (Studler, 2026).

Understanding Lived Experience: An Anthropological Perspective

Anthropologists remind us that experience is never simply individual. People understand their lives through relationships, family, culture, institutions, and social structures (Geertz, 1973; Throop, 2003). Therefore, experience should not be seen as either a purely personal story, as it shaped by memory, beliefs, expectations and social context.

Victor Turner distinguished between the ongoing flow of daily life ("mere experience") and "an experience," a significant event that becomes meaningful through reflection and interpretation. For Turner, experience involves cognition, emotion, and intentionality, highlighting the complexity of human meaning-making (Turner, 1986). Similarly, Clifford Geertz argued that people do not encounter reality directly but interpret it through cultural symbols and systems of meaning and that experience cannot be separated from social context (Geertz, 1973). From this perspective, lived experience is not just about what happens to an individual. It reflects how people interact, interpret and navigate relationships, services, communities, and social systems. This makes lived experience both a personal and a collective form of knowledge. (Throop, 2003; Geertz, 1973)

The Emerging Debate: Lived Experience or Lived Expertise?

One of the key debates today is what we actually mean by *lived experience*.

In policy and practice, lived experience has often been treated as personal testimony, usually a story of adversity, recovery, or survival. While these stories can help reduce stigma and humanise services, they can also unintentionally position people as storytellers rather than as contributors of knowledge and expertise (Clifton et al., 2025).

Increasingly, researchers and advocates argue that lived experience should be recognised as a form of expertise. People who live with disability, mental distress, addiction, poverty, racism, or other forms of exclusion often develop a deep understanding of systems because they navigate them every day. Their knowledge comes from ongoing interaction with services, institutions, and social structures, making it more than simply anecdotal experience (Studler, 2026).

Within this context, a particularly useful distinction has been proposed by Clifton et al. (2025) between *lived experience* and *lived expertise*. In their study, lived experience refers to a person's

direct, embodied experience of disability or other life challenges. Lived expertise builds on this experience and includes knowledge of rights, policy, advocacy, research, community perspectives, and systems change. While everyone with lived expertise has lived experience, not everyone with lived experience develops lived expertise.

This distinction challenges assumptions that separate experiential knowledge from professional knowledge. When aligned with expertise, it reframes lived experience as a potential source of leadership, governance, research, and policy expertise rather than merely consultation. Such thinking aligns closely with disability rights principles such as "Nothing About Us Without Us," which demand active participation in decisions affecting disabled people (Chhabra, 2023).

How lived experience is being used

Numerous initiatives demonstrate attempts to incorporate lived experience into professional systems.

One example is the development of peer support workforces in mental health and addiction services. Peer workers are employed specifically because of their lived experiences and use these experiences to build trust, cultivate hope, and support recovery among those using services (Shalaby et al., 2020; Davidson et al., 2012). Research consistently demonstrates the benefits of peer support. Peer workers enhance person engagement, strengthen therapeutic relationships, reduce stigma, and promote recovery-oriented practice. Their experiential knowledge allows them to understand aspects of distress, recovery, and institutional interactions that traditional clinical education may not fully address (Repper & Carter, 2011; Bellamy et al., 2017).

Other initiatives include lived experience advisory panels, co-production in research, disability peer worker programmes, community-led advocacy groups, and strategic governance roles. Wellcome's mental health strategy, for example, embeds lived experience advisors throughout research governance, project design, implementation, and evaluation processes.

Similarly, disability organisations increasingly involve people with disabilities in policy development, leadership, and service redesign (Wellcome, 2025; Clifton et al., 2025).

Barriers to meaningful inclusion

Despite this progress, significant challenges remain.

A recurring issue across the literature is tokenism. Individuals with lived experience are often invited to share personal stories while having limited influence over decisions. Their contributions may be valued symbolically but not given equal authority to professional expertise (Clifton et al., 2025; McIntosh & Wright, 2019).

Another challenge concerns role ambiguity. Mental health professionals, researchers, advocates, and peer workers or lived experience frequently navigate tensions between professional and experiential identities. Research conducted by Byrne and colleagues shows that many workers feel pressure to conceal aspects of their lived experience or transform experiential knowledge into professionally acceptable forms. This can lead to emotional labour, role confusion, and identity conflict (Friehe, 2024; Byrne et al., 2022).

Stigma also remains pervasive. Workers who disclose experiences of mental health, addiction, or disability may encounter assumptions that their perspectives are subjective, biased, or less credible. Such responses reinforce knowledge hierarchies that privilege formal qualifications and institutional authority over embodied knowledge (Charles et al., 2020; Cooper et al., 2024).

Furthermore, lived experience is not homogeneous. Individuals differ according to age, culture, class, ethnicity, disability type, geography, and life history. Research involving disability peer workers highlights how shared disability identities may coexist with significant differences in institutional experiences, cultural background, or support needs. Consequently, no single person can represent all lived experiences (Mellifont et al., 2024; Wellcome, 2025).

Finally, there are risks of emotional burden and retraumatisation. Sharing personal experiences for organisational purposes may expose individuals to distress if appropriate support, supervision, and safeguarding processes are absent.

Key learnings and recommendations

The emerging concept of lived expertise offers a promising framework for addressing these limitations. By recognising that experiential knowledge can develop into specialised expertise through reflection, learning, community engagement, and advocacy, organisations can move beyond tokenistic participation toward genuine power sharing.

Several key lessons emerge from this analysis:

1. Lived experience should be recognised as a legitimate form of knowledge rather than simply personal testimony. Experiential knowledge emerges from complex interactions between individuals, communities, and institutions.
2. Organisations should distinguish between lived experience and lived expertise. While both are valuable, leadership, governance, research, and policy roles often require additional knowledge, skills, and advocacy capabilities that extend beyond individual experiences. Recognising lived expertise enables more meaningful participation and challenges ableist assumptions about expertise.

3. Meaningful inclusion requires structural change rather than symbolic participation. Organisations must provide clear role descriptions, remuneration, supervision, training, safeguarding measures, and pathways to leadership. Lived experience contributors should be treated as colleagues and experts whose knowledge influences strategic decisions.
4. Researchers and services should adopt participatory and co-production approaches that combine first-person perspectives with broader social and organisational analysis. Anthropology reminds us that experience is both individual and collective, shaped by cultural meanings, historical processes, and institutional contexts.

Embedding lived experience meaningfully therefore requires not only listening to people's stories but recognising their capacity to analyse systems, produce knowledge, and lead change.

Bibliography

- Bellamy, C., Schmutte, T., & Davidson, L. (2017). *An update on the growing evidence base for peer support*. *Mental Health and Social Inclusion*, 21(3), 161-167.
- Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., & Darwin, L. (2022). *Workplace inclusion of lived experience professionals*.
- Chhabra, A. (2023). *Nothing About Us Without Us*.
- Clifton, S., Cooper, E., Bourke, J., et al. (2025). *Disability lived experience and expertise: recognising the expert contributions of people with disability*. *Evidence & Policy*, 21(4), 578-595.
- Davidson, L., Bellamy, C., Guy, K., & Miller, R. (2012). *Peer support among persons with severe mental illnesses*.
- Frieh, E. (2024). *Integrating lived experiences into the role of an expert in mental health services*.
- Geertz, C. (1973). *The Interpretation of Cultures*. Basic Books.
- Repper, J., & Carter, T. (2011). *A Review of the Literature on Peer Support in Mental Health Services*.
- Shalaby, R., et al. (2020). *The role of peer support workers in mental health services*.
- Studler, T. (2026). *Lived experience is often dismissed – but we should recognise it as a form of expertise*.
- Throop, C. J. (2003). *Articulating Experience*. *Anthropological Theory*, 3(2), 219-241.
- Wellcome. (2025). *Embedding lived experience expertise in mental health research*.