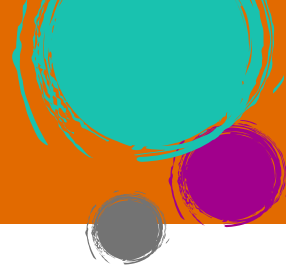


# A GUIDE FOR UNDERSTANDING LIVED EXPERIENCE PERSPECTIVE, EXPERTISE AND RELATED CONCEPTS



The need to define and understand 'lived experience' perspective, positionality and skillset related to it is increasingly necessary in the mental health and social sectors. It is a growth discipline that is open to external viewpoints and judgements that may dilute, diminish or mis-represent the unique lens and value that lived experience is and contributes.

This guide is a collection of key terms related to lived experience. Whilst not definitive it is the beginning of helping people know and be able to differentiate between core components of the concepts.

In putting this together LELAN has drawn on the words and wisdom of lived experience leaders and accepted resource documents that have been researched, co-designed and/or derived after much consideration with people with lived experience and other stakeholders. We acknowledge this is an emerging space and we will continue to reflect on and refine this guide as needed.

## Lived Experience:

When we speak of lived experience at LELAN, we define it as personal experience(s) of mental distress, social issues or injustice 'that have caused life as we knew it to change so significantly we have to reimagine and redefine ourselves, our place in the world and our future plans' (1).

"Lived experience' is used as an umbrella term that conflates the experiences of consumers with the experiences of carers. While some people who have personal lived experience are also carers, and there are some issues where consumer and carer perspectives align, in some cases the interests of consumers are in clear opposition to those of carers. It is not possible for one person to authentically represent both positions at the same time with integrity' (2).



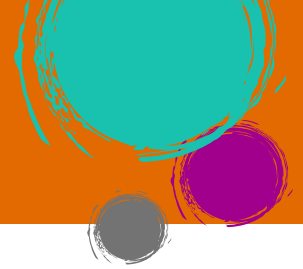
*'To avoid tokenism, both experiences must be recognised as independent and separate of each other and both be given opportunities for involvement and representation matched to the context and issue being explored' (2)*

## Consumer:

Personal experience of mental health challenges, service use, periods of healing/personal recovery (3).

## Carer:

Experience of supporting someone through mental health challenges, service use, periods of healing/personal recovery (3).



## Lived Experience Expertise:

Lived experience expertise is the process of applying what has been learned through a person's lived experience to inform and transform systems, services and individual outcomes for those impacted by mental distress, social issues or injustice. 'Importantly, it's about learning how to use those experiences in a way that's useful to other people' (1).



This expertise is grounded and centred in wider lived experience values and history of the consumer movement

## Lived Experience Leadership:

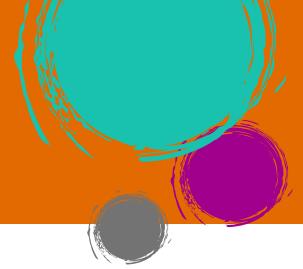
Lived experience leadership is 'where people stand up and speak up for the recognition and valuing of lived experience and advancing the movement. This includes informal and formal activity which promote the values and goals of lived experience as relating to empowerment, peer services, social justice and citizenship. Leaders speak up to influence community awareness, organisational culture, policy and politics; leaders create space, pathways and inclusion with others; leaders prompt and support change' (4).



*'Lived experience leaders connect their personal, professional and socio-political worlds in unique ways to lead change, linking local experience with organisational and systems change endeavours. It operates within and outside of roles, organisations and settings' (5)*

## Lived Experience Workforce:

Lived experience workforce 'is made up of people who are employed in paid positions that require lived experience as an essential employment criterion, regardless of position type or setting. This is a professional approach in which diverse personal experience-based knowledge is applied within a consistent framework of values and principles' (3).



## Lived Experience Worker:

Lived experience worker is anyone who works in a designated role who utilises their lived experience and lived experience values to benefit others with lived experience at either individual, operational or systemic levels. 'It is not just about having relevant personal experience, it's about centring lived experience expertise in what we do to influence and drive change' (2).

Lived experience workers draw on their life-changing experiences of mental or emotional distress, service use, and recovery/healing, and their experiences, or the impact of walking beside and supporting someone through these experiences, to build relationships based on collective understanding of shared experiences, self-determination, empowerment, and hope (3).

Lived experience workers roles can be direct (e.g. peer support roles) or indirect (e.g. lived experience academic, lived experience leader, etc).



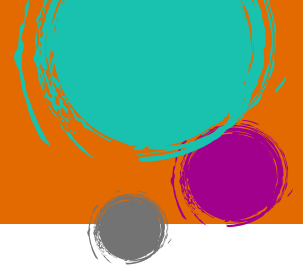
*'Lived experience values are hope, equality/equity, mutuality, empathy, choice, respect, authenticity, belonging/inclusion, interdependence/interconnectedness, justice/human rights' (3)*

## Peer Work / Peer Support:

Peer work / peer support is a subset of the wider lived experience workforces. It predominantly refers to supporting others through recovery.



*'Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain. When people find affiliation with others they feel are 'like' them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert/patient) relationships' (Mead, 2001) (6)*



## Designated Lived Experience Roles:

'Designated lived experience roles include all positions that require lived experience as key criteria, regardless of position type or setting' (3).

## Non-Designated Lived Experience Role:

'Many people in non-designated may identify privately or publicly as having a lived experience. Their lived experience insight is acknowledged as valuable, and the Stages of Development address strategies for increasing the acceptance and valuing of these perspectives within the workplace. However, people in these roles are not employed specifically to work from the perspective of their lived experience. Instead, their positions are informed by different priorities and/or disciplines, and as a result, are not part of the designated lived experience workforce' (3).

## References:

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