

Lived Experience Leadership Analysis

Part of The Meaningful Engagement Toolbox by Collective Threads Initiative

This document is expanded and adapted from Annex 2 in The Meaningful Engagement Handbook.

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What do we mean by “lived experience-led”?

In The Meaningful Engagement Handbook, we shared how some work is led by [impacted people](#) in partnership with their communities and diverse movements. Other work is led by people who do not have lived experience but who care deeply about the issues. When people leading the work do not have lived experience, sometimes they misunderstand the needs and wants of impacted people. The “solutions” they develop may be less relevant or accessible, and the impacted people they work with may report feeling [tokenised](#) or misrepresented.

This has led to an emphasis in many social sectors on the importance of lived experience leadership. For some people, this has led to making space for genuine lived experience leadership. For others, this has provided a new framework to commodify or claim for its perceived credibility, often without the meaningful change that accompanies real leadership by impacted people.

We then may feel confused when we hear claims that an initiative, organisation, or project is “lived experience-led.”

Rather than trying to define what it means when we say “survivor-led,” “lived experience-led,” or that something has [grassroots](#) leadership, we have to figure out what it is we want to know: *Why* are we trying to determine if something is lived experience-led or not? Are we trying to find out if the organisation honours the insights and experiences of those who’ve experienced an issue? Are we trying to find out if the [people with lived experience](#) (PWLE) who are engaged have genuine decision-making power and are integrated throughout the work? For example, an organisation could have a person with lived experience in the [primary](#) executive position but with little or no meaningful support for innovation from the board of directors. Alternatively, a programme could be led by someone with lived experience under an organisation that is not PWLE-led but has near-absolute autonomy over programmatic and budgeting decision-making, meaning that this organisation is functionally more “lived experience-led” than the organisation in the previous example.

When we initially envisioned this document, it was in response to requests for a tool to determine if something is lived experience-led or not. In reality, lived experience leadership is not an on-off switch, but it can be shaped by relational and power dynamics at play. There isn’t a single checklist that can help you determine if something is led by people with lived experience or not, but there are questions we can ask ourselves when considering the role of lived experience in an organisational or programmatic context, and there are dynamics we can learn to recognise.

Below are a few models for understanding “lived experience-led,” along with some considerations.

The person in the senior executive position has lived experience.

Definition used:

An organisation is lived experience-led if its Chief Executive Officer or Executive Director have lived experience. While this definition can be helpful as shorthand, it often overlooks important dynamics.

Dynamics to recognise:

- Sometimes if an executive inherits a dysfunctional organisation, or one that is rigidly hierarchical or founded on [harmful narratives](#) (whether or not it was founded by PWLE), they face roadblocks to the cultural and structural shifts that could foster belonging for all participants.

- An organisation that has a PWLE in its senior executive role but no other PWLE meaningfully engaged may be less “lived experience-led” than an organisation whose senior executive lacks lived experience but in which PWLE are engaged meaningfully and integrated throughout all levels of the organisation.
- Senior executives with lived experience, like all other executives, have a variety of approaches to leadership. Some are effective leaders, and some may not be. Some are ethical, and [some may not be](#). Some may lead through partnership and consensus-building, and some may lead through fear and control. Some may welcome bright leaders around them, while some may feel threatened by bright leaders they don’t feel they can control. These challenges are not unique to those with lived experience but may sometimes be downplayed in tokenistic efforts to uplift lived experience leadership. And when PWLE in particular are in senior executive roles, others around them may struggle to know if, when, or how to offer necessary critical feedback without talking over them or invalidating their expertise.

Questions to ask when exploring an organisation with this model:

- How is the executive supported by the board, and have there been meaningful efforts to build [buy-in](#) for cultural shifts among the staff?
- What are the values that guide the board’s leadership style? What are the values that guide the executive’s leadership style?
- How does the organisation engage differing perspectives from other people with lived experience throughout the different areas and levels of its work, beyond just the executive?
- To whom is the executive [accountable](#)? Does the executive have people they can trust to let them know when they are out of line?¹
- What mechanisms are in place for [grievances](#) to be resolved? How consistently do grievances result in actions taken to find a balanced and accountable outcome?

¹ The SOIL Transformative Justice Project calls this your “accountability pod” and offers guidance on building and working with an effective pod. CTI recommends that all people in leadership or supervisory roles or those with visible “microcelebrity” status in their advocacy sector establish an accountability pod. Learn more at: <https://www.soiltjp.org/our-work/resources/pods>.

The founder has lived experience.

Definition used:

An initiative is lived experience-led if its founder(s) had lived experience. This can be an important indicator, and there have been cases where people with lived experience have been edged out of their own organisations, left on branding materials as “founder” for credibility while losing any decision-making power over the work.

Dynamics to recognise:

- Sometimes, when a person with lived experience co-founds an organisation with someone who does not have lived experience (or who has lived experience and significantly more privilege), their role in the founding may be tokenised or limited by the other founder(s). This should not be assumed to be the case, as many co-founding partnerships are equitable, but it should be considered when reflecting on an organisation’s founding.
- People sometimes found an organisation only to later be pushed out of leadership by their boards, funders, or other partners in the work. When this happens, organisations and their new leadership will often try to keep the messaging of being founded by someone with lived experience without honouring their contributions or truthfully representing how they were treated.

Questions to ask when exploring an organisation with this model:

- How did the founder participate in setting up the structures and values that currently guide the work?
- What level of day-to-day involvement does the founder currently have in the work? If the founder has left the organisation, do they still have any relationship with current leadership?
- How does the organisation currently engage differing perspectives from other people with lived experience throughout the different areas and levels of its work?
- *Reminder: The goal of these questions isn’t to evaluate the founder’s actions, but rather to make sure that surface references to a mythic survivor founder aren’t used to gloss over lack of ongoing meaningful engagement.*

A percentage of staff or people on the board have lived experience.

Definition used:

Over X% of staff or board members have lived experience.

Dynamics to recognise:

- This definition gets us closer to understanding respect for the collective wisdom of [impacted communities](#), and it is still helpful to consider tokenising vs meaningful engagements. For example, a board may be so excited to add someone with lived experience that they bring on someone who lacks knowledge to participate meaningfully in decisions about budgeting and strategy. This could be overcome with a commitment to supporting the new member in learning, and yet many PWLE report feeling like they're on a board simply so the organisation can say it has board members with lived experience.
- An organisation could hire PWLE as peer mentors or in other implementation roles, but not in any key decision-making positions. If over 50% of staff have lived experience but work entirely in non-decision-making or low-paid positions while people without make decisions and get better pay, this raises serious concerns about the power dynamics of the engagement.

Questions to ask when exploring an organisation with this model:

- Does the organisation employ people with lived experience outside of frontline responder and support roles, such as peer support and outreach coordinator? Does the organisation employ people with lived experience in decision-making roles such as upper management and executive positions?
- Does the organisation have people with lived experience in multiple programmes?
- Are people with lived experience in key decision-making and strategic leadership roles? Are people with lived experience in any roles that are not specifically “survivor leadership” roles?
- How does the organisation create supportive, trauma-informed environments that foster the wellness of employees?

Closing Reflections

Remember that our ideal is that organisations do not require disclosure, and even those organisations that know they have some employees who have lived experience will not know all the employees who have lived experience. The purpose of this section of considerations is not to mandate disclosure, but to better understand what a person or organisation means if they say their work is “lived experience-led.” We want to foster meaningful inclusion which takes long-term culture shifts, not simply the performance of inclusion.

One final note: Remember that [feminist](#) and [collective](#) leadership models often work from the ground-up rather than top-down, or may distribute senior leadership roles across multiple individuals. They may be more likely than corporate models to have more intentional checks, balances, and processes for integrating whole-organisation needs and insights into decisions that are made. No matter what the leadership model, thoughtful questions can help you better understand an organisation’s dynamics.



Questions or ideas? Reach out to us at meaningfuleengagement@collectivethreads.org or review the other documents in our Meaningful Engagement Toolbox at collectivethreads.org/meaningfuleengagement.