

Who we are...

The logo for EOTO, LLC is a rectangular graphic. It features a top grey section with the text "EOTO, LLC" in white. Below this is a thin horizontal bar divided into three segments: orange on the left, yellow in the center, and orange on the right. The bottom section is a larger grey rectangle containing the text "Economic Opportunity Trust" in a smaller, white font.

EOTO, LLC

Economic Opportunity Trust



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Nothing for Us, Without Us!

Accessing and integrating
the
Voice of Lived Experience.



The phrase — “nothing about us without us” —a [slogan](#) used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy.

In the 90’s it was a popular rallying cry for people living with disabilities to make the case that unless policies are developed with the support of those who live by them every day, they are missing a key element in the design process.

More recently a slight variation of the phrase has been adopted by racial & cultural groups in the US “Nothing for us without us” and if we dig back in our country’s history we find yet another version “no taxation without representation” - despite the language changes and associated movements the message remains the same..include the people who you are seeking to solve problems for in the discussion and planning of solutions.

What is “lived experience”?

Why is it valuable in policy change and leadership?

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Lived Experience is defined as a person who has first-hand knowledge and experience of an issue they have a deeper understanding of problems faced, systemic barriers, and what needs to be done to address them.

Phenomenology (fee-nom-en-ology) is a form of qualitative research that focuses on the study of an individual’s lived experiences within the world

In simple terms, phenomenology can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it

They can help policy makers avoid unintended consequences that can arise from their proposals, make policies sounder and more applicable.

Evidence shows that policy models that involve those with lived experience and **prioritize their needs**, are typically the most sustainable and scalable.

By including people with lived experiences in a meaningful and thoughtful manner in consultation processes, we enrich the policy process and those who undertake it. More importantly, we also ensure that policies we implement will work for the people whose lives they are intended to improve.

People with lived experience and lived experience professionals.

Everyone has some experience that would help develop a better way of handling many of life's challenges but there are some lived experiences such as with physical and mental health and substance use issues that can prepare the right individuals for a career in supporting others such as certified peer support.

Human beings, who are almost unique in having the ability to learn from the experience of others, are also remarkable for their apparent disinclination to do so.

—Douglas Adams

It is imperative that we understand what new policies will do in the real world, not just how they would work for us if we were in the situation the policy/program seeks to address. People often make the mistake of thinking what would work for us will work for everyone. That is simply not so.

Despite the fact that humans are one of few animals who can learn from the experiences of others, we are often loath to do so. Perhaps this is because we assume that similar circumstances could never befall us. Perhaps this is because we assume that, if placed in the same situation, we would make wiser decisions. Perhaps it is because we assume the subjective experience of an individual is not as reliably informative as objective data collected from external reality.

How can I connect to and welcome people with lived experiences into my work or organization?

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1. CREATE SAFER SPACES that support open dialogue across diverse perspectives

Instead of a **calling in** people with lived/living experience **on demand** to advise on internal operations, consider **resourcing autonomous and self-determining spaces** for people with lived/living experience. These safer spaces allow the voices of lived/living experience to be heard. They empower people with lived/living experience to reflect on and discuss issues privately before bringing consensus proposals back to the larger group.

- Affinity and special interest groups (town hall style public video meetings and radio shows)
 - Panel discussions/Q & A sessions hosted by local groups
- A. HOST ACCESSIBLE MEETINGS Develop meetings and agendas with people in mind
- Consider all “isms” (racism, genderism, ableism, classism...)
 - Provide more than one pathway to engagement (in person and video access, recording playback sessions with live Q&A)

A. CREATE OPPORTUNITIES FOR ENGAGEMENT Reframe the dominant narrative

- Flip the script, “Work before Play” flipped on its head - Advocacy is only heard once trust is built
- Focus on “intent vs impact”
- Those with lived experience should not be seen as service recipients, objects of policy-making, or research subjects.

DIVERSIFY REPRESENTATION AND DEEPEN ENGAGEMENT Foster an inclusive space that reflects the diversity of the community

How do I ensure that their experience is valued and my approach is equitable?

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1. Ensure that no one incurs a cost to engage Different people require different supports to participate

If a group is unable to compensate participation-related expenses, they then need to ensure that partners with lived/living experience are able to decide freely how and to what extent they would like to contribute their time. For example, it might be more appropriate for that group to create engagement opportunities that are open to all, instead of creating an advisory committee that cannot yet be adequately resourced.

different people require different supports to participate. compensation furthers the idea that everyone's time and contributions are valued from recognition to action. It demonstrates respect, supports diverse voices to be heard, disrupts power imbalances, and challenges some of the inequities that lie at the root of poverty.

1. Suspend your own attitudes, beliefs, and suppositions in order to focus on the participants' experience

By not making assumptions, groups re-value participants as individuals. This builds trust and encourages participation.

Employ an academic approach, *bracketing*, (scientific research and math) a process through which the researchers set aside—or bracket off as one would in a mathematical equation—previous understandings, past knowledge, and assumptions about the phenomenon of interest.

1. **Level power dynamics with capacity building, training and mentoring opportunities.**

Partners with lived/living experience can find value in training, in the areas of leadership, communication, public speaking, and advocacy, and system navigation. Combining training with engagement opportunities can support them to move from storytellers, to community advocates, to decision makers.



What do I do with this new information to help build my own personal leadership abilities as well as the capacity and impact of my organization?

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1. OPEN UP DECISION MAKING PROCESSES Authentic engagement is about sharing power

create pathways that empower individuals to move into leadership roles, such as Chair, Co-Chair, and facilitator positions. strive for 25% - 50% representation of people with lived/living experience across all boards, tables, committees, sub-committees, action teams, and engagement opportunities.

Groups can hold themselves accountable to more diverse and deeper engagement by establishing goals.

Small, tangible targets can keep a group on track, while bigger, loftier targets can inspire longer-term actions.

1. INVEST IN CAPACITY BUILDING skill development and mentoring to promote teamwork and trust

Anti-oppressive training, ideally led or co-led by partners with lived/living experience, can deepen understanding of the invisible power relationships that manifest within and outside of a group. It can support groups to work more respectfully and effectively together, since instead of requiring colleagues with lived/living experience to fit into a group's current culture, this approach challenges the group to shift the way that they themselves work.

Mentorship and peer-support models promote mutual understanding and reciprocal learning across individuals and sectors.

1. LEVEL POWER DYNAMICS

recommendations made by people with lived/living experience often do not make it to policy, and how this lack of follow-through greatly hinders the development of trust. They therefore recommended that groups specify how they would ensure that recommendations, decisions, and solutions from people with lived/living experience would be actioned. One way to do this is for a group to reflect on the extent to which they are comfortable, willing, ready, and able to take recommendations forward, for example by leveraging resources and networks, or by advocating for policy and systems change.

over time, as engagement of people with lived/living experience deepens, local champions with lived/living experience become increasingly recognized in the community. As a result, they get called on more often for advisory purposes by governments, businesses, non-profits, and community members seeking their advice and expertise. This helps to embed their perspectives in decision-making processes across the community.

Questions & Comments?

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