THE STEPPINGUP INITIATIVE

Centering Lived Expertise:

How to Meaningfully Elevate the Voices of People Directly Impacted by the Criminal Justice and Behavioral Health Systems

Introduction

The behavioral health field has long understood the impact and importance of engaging people with lived experience to support treatment and recovery and improve access to services.[1] Despite increased involvement and hiring of people with lived experience by criminal justice and behavioral health organizations, especially as peers and peer specialists,[2] the full potential and impact of elevating the voices of lived experience in the criminal justice system has not been realized.[3]

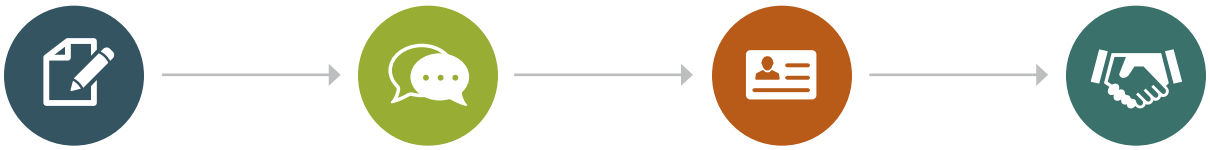
In addition to helping others navigate the complexities of the behavioral health and criminal justice systems, people with lived expertise provide unique and crucial perspectives that can inform the development and implementation of effective policies and practices that promote success and improve outcomes at the individual and system levels.

Integrating the voices of people with lived experience in processes that evaluate policy, programming, and practice is essential to championing equity in general and racial equity in particular.

This brief summarizes guidance developed by a panel of people with direct experience in both the criminal justice and behavioral health systems about how to meaningfully engage and partner with people with lived experience to advance policies and practices at this intersection.[4] State and local officials, criminal justice practitioners, behavioral health organizations, and other interested parties wishing to engage the voices and expertise of people impacted by these systems can use the insights outlined in this resource to develop engagement strategies that meet their needs and ensure strong, fruitful partnerships.

A Continuum of Meaningful Engagement

Organizations, state and local officials, and other entities seeking to engage people with lived experience have a range of options, as meaningful engagement occurs along a continuum ranging from less intensive strategies to more involved and extensive approaches. The value of the engagement is not necessarily tied to the intensity, duration, or complexity of the collaboration because less intensive strategies can still be meaningful to all parties involved when implemented thoughtfully. As depicted below, the engagement strategies can range from less intensive *outreach*, such as surveys and public forums, to more in-depth activities focused on *collaboration and shared leadership*.



Outreach

Surveys and public forums can be helpful for gathering a breadth of information from a large group of community members. This can be a reasonable option to consider for engaging people with lived experience when operating with limited resources and under significant time constraints. For instance, administering a survey to program participants is a common mechanism for gathering participant feedback around program operations and impact.

Consultation

Consulting people with lived experience can occur through interviews, focus groups, and short-term advisory panels. These approaches allow for more in-depth exploration of specific topic areas. The Lived Experience Advisory Panel that helped develop this brief represents an effective example of consultation, since this group had a very specific and targeted, time-limited role or "assignment."

Hiring

Hiring people with lived experience creates opportunities for that perspective to be infused into organizational policies and practices and to truly inform organizational efforts. This should go beyond peers and peer specialist roles to include hiring people with lived experience as social workers, county and criminal justice staff, case managers, managers, and organizational leaders to ensure their perspectives are embedded across projects and departments.

Collaboration and Shared Leadership

Engaging people with lived experience from start to finish in developing and implementing initiatives, policies, or practices is part of a more profound engagement process that can lead to better outcomes for people and communities most impacted by the behavioral health and criminal justice systems. This approach can include, but is not limited to, having lived experience representation on a task force, steering committee, or similar advisory body, so that they are consistently engaged in the information-gathering, contextualizing, and decision-making process. This could also involve incorporating their perspectives into evaluation and quality improvement efforts and, most importantly, entails consistent and longer-term engagement.

"When we say 'lived experience,' we mean knowledge based on someone's perspective, personal identities, and history. When we say 'lived expertise,' we are talking about the summation of someone's perspective, personal identities, and history coupled with their professional or educational experience. Respectfully, there is a difference."

Philip "Change Agent" Cooper, Lived Experience Advisory Panel Member

What is the difference between "lived experience" and "lived expertise"?

Lived experience refers to the personal experiences and firsthand knowledge that people have gained through their own life journeys. This term is often used in the context of mental health, substance use, or other life challenges. People with lived experience have directly experienced these challenges, and they draw upon their own experiences to provide insights, empathy, and support to others facing similar issues. Lived experience emphasizes the personal and subjective nature of the experiences.

Lived expertise is a term that acknowledges that people with lived experience can develop expertise and knowledge related to the challenges they have faced. It implies that people who have personally navigated mental health issues, substance use, or other difficulties can become experts in these areas. They may have a deep understanding of the systems, services, and barriers related to their experiences and can use this expertise to advocate for change, offer guidance, and contribute to policy development and program design. Lived expertise focuses on the knowledge and insights gained through lived experience.

While these terms are related, the distinction lies in the emphasis on personal experience in "lived experience" and the acknowledgment of acquired knowledge and expertise in "lived expertise." Both terms recognize the value of individuals' unique perspectives and contributions, whether as peer support providers, advocates, or leaders, in addressing issues related to their experiences. The choice of terminology may depend on the context and the specific focus of a discussion or initiative.

Considerations for Effective Engagement

Regardless of the method of engagement, successful engagement must be thoughtful, systematic, and reciprocal instead of extractive.[5] "Engagement is meaningful when people can work with one another to learn about issues, understand others' views, address equity and differences, generate ideas, and make plans for action."[6] These things often cannot be accomplished through one meeting or process. Additionally, people with lived experience in the behavioral health and criminal justice systems have often experienced negative consequences that may shape their perceptions of the world, which requires thoughtful considerations for effective engagement. Before beginning the engagement process, organizations and leaders need to clearly understand their own intentions:

- **What are the primary goals of engagement?**
- **What resources (such as staff time and funding for compensation) are available to support the engagement strategy?**
- **What are the expectations, risks, and rewards for all parties involved?**

Beyond these initial questions, there are a number of factors to take into consideration when embarking on these engagement activities. By embracing these considerations, organizations can guarantee that engaging people with lived experience goes beyond checking a box, leading to more impactful and inclusive programs that promote equity. Incorporating these measures can demonstrate to people with lived experience that they are truly cherished and influential participants in behavioral health and criminal justice initiatives. To guide organizations through this engagement process, these factors and considerations are broken down into three phases in the process of engagement: **Setting the Stage for Success**, **Meaningful Engagement in Action**, and **Follow-Up and Sustainability.**

Setting the Stage for Success

Transparency: At the outset, organizations should be transparent about their goals and intentions involving people with lived experience. Communicate the role that information shared by people with lived experience will play in shaping policies, programs, or practices. Ensure people are aware of their expected contributions and any inherent limitations at their level of participation. This means proactively reaching out to share information and offer transparency on the mission, goals, tasks, and impacts of past and current policies, programs, and practices.

Trust: Building and maintaining trust should be a foundational consideration of any engagement effort. People with lived experience may need time to build more trust in institutions or organizations due to negative past experiences. With that in mind, intentionally and proactively address any concerns, maintain two-way communication, and collaboratively troubleshoot challenges that arise as part of the initial outreach and engagement process.

Diverse Representation: Be sure to engage people with lived experience who represent diverse backgrounds, experiences, and viewpoints. Design outreach, recruitment, and application processes to be inclusive of people from diverse cultural, social, and economic backgrounds. Recruitment materials, processes, and procedures should be accessible, flexible, and inclusive in order to reach a diverse group of people whose lived experience can directly inform more effective and compassionate solutions. Further, ensure that engagement processes are responsive to and respectful of cultural differences and practices.

> *However, take care to avoid **tokenism**, or merely including people with lived experience for appearance's sake without genuinely valuing their contributions. Organizations should also avoid tokenizing a single person to represent an entire group. Seek multiple perspectives by fostering relationships with organizations that serve impacted communities and local civic, advocacy, religious, and business leaders who community members trust.*

Awareness of Stigma and Discrimination: People with lived experience may face stigma and discrimination related to their mental health, substance use, or criminal justice involvement. Organizations must understand how their policies and practices may reinforce stigmas or discrimination, which can deter them from speaking out or hinder their ability to provide input, collaborate, or co-design.

Technical Assistance and Training: Identify internal gaps in either knowledge or practice before engaging people with lived experience to determine whether receiving technical assistance would be beneficial. Organizations may need training to engage and partner with people with lived experience successfully. It is also important to provide training and support for people with lived experience to fully engage in the process, as a lack of skills or training in engaging in advocacy or decision-making processes can hinder participation or limit their contributions. This might include trainings on communication, policy knowledge, and advocacy skills. Moreover, all parties involved in the engagement process should have a shared understanding of what to expect and how to communicate effectively with one another.

Resources and Accessibility: People with lived experience should be fairly compensated for their time and valuable contributions to informing policymaking, programming, and practices. Organizations that want to incorporate the voices and expertise of people with lived experience should provide ample financial resources to pay for that time and effort, at the rate they would other subject matter experts. Fair compensation acknowledges the value of their input and ensures they are not being exploited.[7] Additionally, ensure that other logistical constraints or barriers (such as language, transportation, accessibility, and timing) are addressed to secure individuals' participation in meetings, events, or advocacy efforts.

Meaningful Engagement in Action

Cultural Competence*: Organizations should ensure that their approach is culturally competent and sensitive to the diversity of experiences among people with involvement in the behavioral health and criminal justice systems. Just as their experiences with these systems have shaped their perspectives, so have their cultural identities. To share nuanced insights, it can be important for people to also share about their cultural identities. Set rules and parameters that will guide meetings and the work and create a space where people with lived experience feel comfortable sharing their cultural identity. Avoid making assumptions or stereotypes. Insensitivity to cultural diversity can create barriers for people from different backgrounds, including reluctance to openly share their perspectives.

Trauma-Informed Approach: For people with trauma in their past, participating in specific settings or discussing certain topics may trigger emotional distress or re-traumatization. Recognize that participation may require time and emotional support for those with lived experience. This may include providing flexible schedules and resources (such as education, access to mental health services, and their own peer support) to facilitate their involvement.

Additionally, as an organization begins to employ more people with lived experience, it is important to create a trauma-informed culture that is both welcoming of staff sharing their lived experiences and supportive of other staff that may have emotional reactions to these stories. It can be problematic to expect the immediate cultural adaptation of both staff with and without lived experience. Human resources departments should have trauma-informed resources and support available to all staff to navigate these potential difficulties.

Communication: Foster open and honest communication between people with lived experience and other behavioral health and criminal justice personnel involved in the work to reinforce trust in the collaboration and ensure contributions are heard and understood. Encourage constructive dialogue and the sharing of differing viewpoints. Additionally, when possible and appropriate, organizations should act on the insights and recommendations provided by people with lived experience or provide a rationale for not doing so. Demonstrating and communicating how their input has an impact is essential for building and strengthening trust.

Active Involvement in Decision-Making: Ensure that when people with lived experience are included in processes to evaluate or change policies or practices, their insights will be put to good use. People with lived experience need to be actively and equitably involved in decision-making at all appropriate stages of program and policy development. Organizations should identify areas of the process in which people with lived experience can be the decision-makers or where their input will influence the decisions made.

Feedback Mechanisms: Establish mechanisms for feedback to ensure that people with lived experience can provide input on the process and offer suggestions for improvement. Committing to ongoing self-assessment and improvement demonstrates that the input and guidance provided by people with lived experience are valued. A feedback mechanism also creates the opportunity to identify and address issues or challenges that may arise during the collaboration or partnership.

**Cultural competence is widely accepted to be defined as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable the system, agency, or professionals to work effectively in cross-cultural situations."*

Follow-Up and Sustainability

Meaningful Follow-Up: All too often, when engaging with people with lived experience, organizations seek their feedback but provide no opportunity for them to learn how their contributions are used to inform programs, policies, or practices. It is important to always follow up with participants to not only acknowledge their contributions, but also share any deliverables or policy changes that stemmed from the insights they shared. Ideally, the review and approval of any resources that derive from the engagement process should be baked into project wrap-up processes. This closes that feedback loop and facilitates shared ownership of the work.

Evaluation and Accountability: Organizations should regularly evaluate their initiatives and processes to ensure that tokenism does not usurp genuine, valuable involvement. Leaders engaged in processes incorporating the voices and expertise of people with lived experience wield power and should use it to hold their organizations accountable for upholding meaningful engagement. Regularly reevaluating engagement processes will ensure they continue evolving toward more meaningful participation.

Where to Begin?

This document provides a roadmap and guidelines for organizations interested in partnering with people with lived experience at the intersection of criminal justice and behavioral health. There is no single prescribed method for lived experience engagement, but there are key considerations that should guide that engagement process from the very early stages of planning the work to ensure that it is a rich and meaningful effort for all parties involved. While this process can seem daunting, failing to take the steps necessary to do this work the right way undermines the importance of elevating the voices of people with lived expertise. People who have been directly impacted by these systems are essential subject matter experts that deserve a seat at the table. And as the Lived Experience Advisory Panel members shared, "We are the table." The insights of people with lived experience often illuminate the true impact and potential collateral consequences of policies and practices implemented within these systems. By taking the first step to design and implement an engagement strategy, the possibilities and potential benefits are boundless.

Resources for Stakeholders Wishing to Engage People with Lived Experience

Building Successful Partnerships with Peer-Run Organizations

Key Stakeholders: People With Lived Experience

San Mateo County Health Lived Experience Academy

Oregon Center on Behavioral Health & Justice Integration

U.S. Department of Health and Human Services: Recruiting Individuals with Lived Experience

U.S. Department of Housing and Urban Development (HUD) Exchange: Centering Lived Experience Resources

Wisconsin Healthiest State: Centering Voices of Those Most Impacted in Health Equity Efforts

New Philanthropy Capital (NPC) Centering Lived Experience: A Strategic Approach For Leaders

Organizations Led by People with Lived Experience and Expertise

VOTE: Voice Of The Experience New Orleans

JLUSA: Just Leadership USA

California Association of Mental-Health Peer Run Organizations

Endnotes

1. Reham Shalaby and Vincent Agyapong, "Peer Support in Mental Health: Literature Review," *JMIR Mental Health* 7, no. 6 (2020):e15572, https://doi.org/10.2196/15572.

2. In the context of behavioral health, a peer refers to someone who shares the experience of living with a psychiatric disorder and/or addiction. Peers can use their lived experience to help and motivate similarly impacted people with their recovery and access to services. Peer support specialists are defined as "mental health workers living with a psychiatric disorder who are trained to counsel or assist others with experiencing and living with the same condition." Certified peer specialists receive formal training and certification on a model of mental health and substance-use peer support.

3. Health Equity Solutions, *Transforming Community Engagement to Advance Health Equity* (Hartford, CT: State Health and Value Strategies, 2023), https://hesct.org/publications/transformational-community-engagement-to-advance-health-equity/.

4. In 2023, The Council of State Governments (CSG) Justice Center partnered with C4 Innovations to create the Lived Experience Advisory Panel (LEAP), which consisted of eight people from across the country with diverse backgrounds and lived expertise in the behavioral health and criminal justice systems. The LEAP met on several occasions and conducted focus groups with other people with lived experience to develop the guidance contained in this document. Beyond the work contained here, the LEAP has been instrumental in shaping efforts to advance racial equity through the Stepping Up framework.

5. Syreeta Skelton-Wilson et al., *Methods and Emerging Strategies to Engage People With Lived Experience* (Fairfax, VA: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, 2021), https://aspe.hhs.gov/sites/default/files/documents/62e7a64c60e10c47484b763aa9868f99/lived-experience-brief.pdf.

6. "Guide to Community Engagement Part 1," Advancing Pretrial Policy & Research, November 2022, https://advancingpretrial.org/improvement-guide/guide-to-community-engagement-part-1/.

7. For practical guidance on creating an equitable compensation plan, see Mel Langness, Saidy Cedano, Justin Winston Morgan, and Elsa Falkenburger, *Equitable Compensation for Community Engagement Guidebook* (Washington, DC: Urban Institute, 2023), https://www.urban.org/sites/default/files/2023-08/Equitable%20Compensation%20for%20Community%20Engagement%20Guidebook.pdf; The LEAP members, for example, were compensated at the federal rate established for subject matter experts.