



A PRODUCT OF DELTA CENTER CALIFORNIA

Elevating People With Lived Experience

A Workbook of Strategies for Organizational Change Shaped by People with Lived Experience

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Introduction


This workbook is a result of the knowledge, experiences, vulnerability and thoughtful perspectives of a small group of leaders with lived experience including Khatera Aslami-Tamplen, Keris Jän Myrick, and Rayshell Chambers. This group of mental health champions have the lived experience of managing a mental health condition, leading and advocating for mental health within healthcare systems and as certified peer support specialists. Interviewed by Jennifer Clancey, a member of the Delta Center California State Roundtable, the strategies outlined here came directly from their conversation and the work they continue to do.

Lived experience is defined as “personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people¹.” People with lived experience (PWLE) are considered experts by experience within their diagnosis or health condition². For too long, research, public health, and healthcare have been designed by people who do not actually have the direct experience of living with specific health conditions or needing the services that programs intend to deliver to be helpful.

Lived experience is valuable because it brings a deeper understanding of the challenges and barriers that individuals face in accessing and receiving services and care. Many organizations are faced with the desire or need to create an environment that hires, promotes, supports, and leverages the strengths of people who would be their members, clients, or patients. A culture where people feel safe openly talking about their lived experience and the impact of those experiences on the work of the organization. A place where having this expertise is seen as a point of pride. Many times, people with these lived experiences are already working within these organizations but may not feel safe to disclose their personal history to their colleagues.

¹Oxford Reference. “Oxford Reference – Answers with Authority.” Oxfordreference.com, 2019, <https://www.oxfordreference.com/display/10.1093/oi/authority.20110803100109997>

²Basset, Thurstine, et al. “Lived experience leading the way: Peer support in mental health.” *London: Together UK* (2010).



This workbook has been developed to assist organizations with recruiting, supporting, engaging and promoting individuals with lived experience. It provides strategies and considerations to support organizational culture and practice that elevate people with lived experience; specifically those who:

- Are currently or have previously been impacted by mental health and/or substance use conditions. This includes those who have experienced a condition personally or are family members, caregivers, or supporters of those with mental health and/or substance use conditions.
- Individuals who have received or sought care in the Medi-Cal system.

This Work Requires A Change in Culture

The need for organizational infrastructure to support the recruitment, engagement, and promotion of PWLE is essential. Although well intentioned, many organizations that set out to be more inclusive and diverse don't appreciate or emphasize the need for culture change as a north star of equity and justice. This brings systemically oppressed groups into environments that can perpetuate harm. It puts the burden of creating change on one person, or one team, when the system needs to change. The consequence of this is continued discrimination, stigmatization and tokenization. Our hope is that this workbook can be a starting point to making those organizational culture shifts. If supporting PWLE is a priority for you, ensure the culture of your organization is one that supports and does not perpetuate harm. Avoid the risks of exploiting and/or tokenizing lived experience by instead ensuring thoughtful, intentional, inclusive, and purposeful engagement that entrust and empower individuals with lived experience.

The concepts in this guide are applicable to a wide variety of healthcare organizations including but not limited to:

- Foundations
- Managed care organizations
- Government agencies like State and County Health Departments
- Health Plans
- Hospitals
- Healthcare providers
- Community Based Organizations

How To Use This Workbook

This workbook provides five overarching strategies to ignite an organizational culture change that supports people with lived experience:

1. Understanding the Why
2. Leadership
3. Education and Training
4. Values, Policies, and Processes
5. Hiring practices

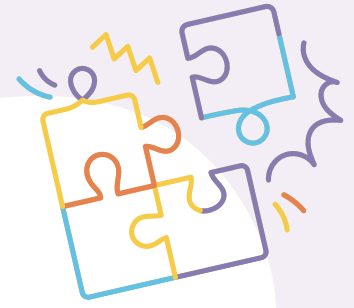
The ideas represented are not all-encompassing, but are tools for deepening conversations.

Each section provides considerations for improving organizational culture and activities, and tools for moving from idea to implementation. It was also designed with the belief that we are all leaders and all have a role to play in creating a culture that is inclusive, equitable, and supportive for all. Staff at every level can utilize this workbook; however, leadership buy-in is essential for substantial, sustainable culture change. **We recommend that you don't do this work alone. Grab your team, bring this work into an existing committee, and gather interdisciplinary coworkers. Real change happens with collective support to shift the status quo.**

This workbook is a product of Delta Center California. Delta Center California is an initiative supported by the California Health Care Foundation and the Robert Wood Johnson Foundation and led by JSI Research & Training Institute, Inc. It brings together behavioral health and primary care leaders to accelerate care improvement and integration through policy and practice change.



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Strategy 1: Making the Case for Why

Clearly articulating why elevating lived experience is important to you and your organization is like a North Star. It can ignite and reignite energy toward creating a more inclusive culture.

1

Hiring, supporting, and promoting PWLE is an asset to an organization. It brings a deeper understanding of the challenges and barriers that individuals face in accessing and receiving care. This can help to inform and improve policies and practices at the organizational, local, and state level.

2

Leaders with personal experience can serve as role models and advocates for the individuals you serve and can help to reduce the stigma surrounding mental illness, substance use disorder, or receiving services through Medi-Cal. Leaders who bring their personal experience to their roles can also create a more supportive and understanding work environment, which can lead to improved employee morale and engagement.

3

Having a diverse range of perspectives and experiences represented in leadership and throughout an organization can help to improve quality of care, workplace innovation, and team communications.³

4

Knowing that an organization values, respects, and cultivates an environment that truly embraces diversity, equity and inclusion (DEI) can enhance its reputation and credibility.

5

Creating a culture that supports PWLE benefits current staff as well as new employees being onboarded.

³Gomez, L E, and Patrick Bernet. "Diversity improves performance and outcomes." *Journal of the National Medical Association* vol. 111,4 (2019): 383-392. doi:10.1016/j.jnma.2019.01.006

Workbook Activity 1



REVIEW

Methods and Emerging Strategies to Engage People with Lived Experience. Improving Federal Research, Policy and Practice from the U.S Department of Health and Human Services. Pages 8-13 specifically highlight various roles of individuals with lived experience and define meaningful engagement

REFLECT

- *Why is doing this work of including folks with lived experience important to you?*
- *What 'why' is missing from this list?*
- *Think of a story that highlights why lived experience in behavioral healthcare or the Medi-Cal System is important to you (you can use a persona or a real person in your life). Feel free to use this space to write down your reflections.*

ACT

Write a commitment statement indicating how you will “make the case for why” within your organization.

Strategy 2: Leadership

For lasting change, leadership is essential. This includes leadership from those in formal positions of power but also includes leadership from those willing to advocate and advance change at any level.

1

The most integrated, sustained, and consistent form of engagement is to involve individuals with lived experience in leadership positions. This includes leadership in roles that are not always related to their specific experiences which are often roles related to peer support, and diversity, equity, and inclusion.

2

Inquire about ways to support individuals with lived experience in the workplace. Work to ensure that PWLE receive as much value as they add.

3

Encourage those already in leadership positions to model openly sharing about their lived experiences with behavioral health.

- Note when sharing about a family member/loved one's lived experience, leaders should only share what that person is comfortable with. They should acknowledge that they are not speaking for someone else, but instead speaking of their own experience as a family member.

4

If creating a new leadership role specifically for a person with lived experience (i.e. Director of Lived Experience), that leader should have the opportunity to hire a team to support their work. This will prevent too large a burden from being placed on one person.

5

Organizational leadership must take a strong position on not stigmatizing or tokenizing employees with lived experience. Acts of discrimination must not be tolerated.



Workbook Activity 2



REVIEW

Read through the quotes below from the interview that shaped this work. These are the ideas of people with lived experience in leadership positions

"[Leadership] really does make a big difference. How is the leader or the person at the top? Do they have training in [valuing and elevating lived experience] ? Do they have their own humility to be able to see the value and importance of these roles, and create that environment where the person in it feels empowered, and not like a token."

"I don't think our leaders understand, and I'm gonna use the term even though I don't like it, but they don't understand serious mental illness."

"Do you have something where you're actively engaging the community, people with lived experience, and people receiving services? [Are you] reporting it, showing up more than once a quarter. Are you compensating [PWLE]? Are you meeting their needs? [Are there] more roles for people that are actively engaged on a regular basis and helping you address the system issues?"

REFLECT

- *Does your organization's leadership exhibit the traits, or perform any of the activities mentioned above?*
- *How has that impacted the culture of the organization in relation to valuing lived experiences? Feel free to use this space to write down your reflections.*

ACT

Brainstorm a potential way(s) that your organization could better support PWLE in obtaining and filling leadership positions. If you are currently a leader who identifies as a PWLE, consider what workplace culture would allow for you to share about those experiences if you have not already? Create an action plan that could make this culture the new status quo.

Strategy 3: Education & Training

Ongoing education and training help staff build the knowledge and skills necessary to contribute to a supportive organizational culture for PWLE. Assessing your readiness to engage people with lived experience can be an effective tool to gauge what education and training resources are most relevant.

1

Engage and pay PWLE in the curriculum development and training of individuals, teams, and organizations.

2

Organizations should facilitate required training on the importance of respectfully engaging and elevating PWLE, avoiding tokenizing, stigmatizing, or otherwise discriminating against PWLE.

3

Training should be done at the time of onboarding and in an ongoing manner.

4

Training about lived experience can be integrated into Diversity, Equity and Inclusion training.

5

Organizations must recognize that systemic change takes time.



Workbook Activity 3



REVIEW

Although it centers a different lived experience, the National Survivor Networks Toolkit titled Meaningful Engagement of People with Lived Experience provides surveys, tools, and evaluation guidance to measure your organization’s progress toward meaningful engagement (see page 32). Review and take an assessment.

REFLECT

- *What training does your organization do currently? Does it include PWLE?*
- *Based on your assessment results from the toolkit mentioned above, what are opportunities to improve? Feel free to use this space to write down your reflections.*

ACT

How will you update your training plan? Come up with an approach and advocate for this with staff who have the power to change it.

Strategy 4: Values, Policies & Practices

Organizational values show up in the policies and practices of the organization. Examining those values and ensuring they name the importance of lived experience promotes a culture of inclusivity that can benefit the organization as a whole and people with lived experiences.

1

Support current and future employees who might also be clients/recipients of services provided by the organization, as well as underserved, inappropriately served, and other marginalized communities -- it will take effort and time but is needed.

2

Embrace the intersectionality of lived experiences.

3

Examine if there is any language on an organizational level that discusses diversity, equity, and inclusion (DEI). If so, does it outline the organization's commitment to hiring, engaging with and uplifting the voices of PWLE?
◦ If no statement exists, can one be created that highlights the organization's commitment to PWLE?

4

Create internal policies that dictate how the organization will engage with and elevate PWLE. Are there internal pathways for PWLE to move into leadership positions?

5

The burden of culture change must not be placed on one individual, group, or department.



Workbook Activity 4



REVIEW

The Delta Center California Panel Discussion on Building and Sustaining a Diverse and Representative Integrated Workforce.

REFLECT

- *What are your organizational values?*
- *Do you have a set of values that everyone in the organization is aware of? If not, perhaps now would be a time to engage in conversation and create these.*
- *Which of your organizational values relate to your commitment to hiring, engaging with, and uplifting voices of PWLE? Feel free to use this space to write down your reflections.*
 - *Here are a few Diversity, Equity and Inclusion Statements that may give you some inspiration. Explore what resonates with you? What doesn't? [The California Community Foundation](#), [National Alliance on Mental Illness](#)*

ACT

Create language to add to your existing DEI statement that uplifts your commitment to engaging PWLE.



Strategy 5: Hiring Practices

Bringing PWLE into decision-making and leadership roles requires an organizational culture shift and a shift in hiring practices.

1

Create opportunities to recruit PWLE for open positions.

- Example: Job postings should include a statement indicating the organization is actively hiring PWLE.

2

During job interviews, ask questions that allow and encourage applicants to discuss their lived experience, if comfortable. This signals to applicants that their lived experiences are valued by the organization and that it is acceptable to talk about one's lived experience. Secondly, these kinds of interview questions often prompt applicants to discuss their interest in and passion for their work on a more meaningful level.

3

Roles for PWLE should be intentionally and thoughtfully designed to avoid tokenizing or pigeonholing a person into representing or being a spokesperson for all PWLE.



Workbook Activity 5



REVIEW

Recruiting Employees with Lived Experience into the Public Mental Health Workforce (page 89) and Barriers and Opportunities Section from Meaningful Engagement of People with Lived Experience (pages 22 - 23) to get a better understanding of considerations for hiring PWLE.

REFLECT

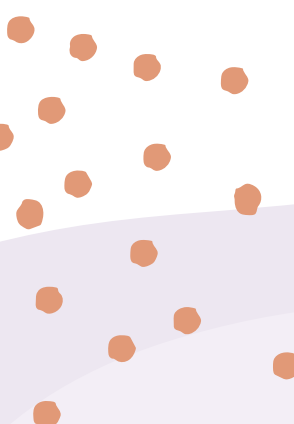
- *Does your organization have hiring practices in place that invite and uplift PWLE? If not, consider what steps from the resource feel attainable and approachable.*
- *What does it look like to “respectfully engage and elevate PWLE?” Draw a picture. Talk about it. Feel free to use this space to write down or draw your reflections.*

ACT

Draft a statement that could be included in a job posting indicating that your organization is actively hiring PWLE.

Draft relevant questions that could be included in a job interview that would highlight lived experience.

Share these with staff who are in charge of hiring processes.



Additional Resources

This is not the only resource that can help you engage people with lived experience. Below are various toolkits, resources, and workbooks to support you on your journey to meaningfully engage and elevate people with lived experience.

- The U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation’s [Methods and Emerging Strategies to Engage People with Lived Experience](#)
- 100 Million Healthier Lives and the Institute for Healthcare Improvement’s [Engaging People with Lived Experience Resources](#)
 - 100 Million Healthier Lives and the Institute for Healthcare Improvement’s [Getting Started Engaging People with Lived Experience Toolkit](#)
- The National Survivor Network’s [Meaningful Engagement of People with Lived Experience](#): A framework and assessment for measuring and increasing lived experience leadership across the spectrum of engagement
- [Toolkit for Employing Individuals with Lived Experience Within the Public Mental Health Workforce](#)
- [The Lived Experience Academy](#) for individuals who identify as having experience with mental health and/or substance use challenges, and/or their family members

