

Integrating People With Lived and Living Experience Into Overdose Prevention and Response Programs

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Introduction

Whether as staff, consultants or members of advisory boards and workgroups, people with living and lived experience (PWLE) of substance use, chaotic substance use and recovery bring a valuable perspective to overdose prevention efforts. It is critical to remember that communities of people who use drugs (PWUD) innovated many impactful harm reduction practices, and grassroots community overdose prevention strategies often are the most effective if scaled up. PWLE can provide insights into the complex realities and challenges of substance use and the unique overdose prevention needs of PWUD; this can lead to more empathetic, realistic and effective overdose prevention strategies that are grounded in the nuanced understanding of individuals' needs and pathways to recovery.

However, it can be difficult to know how to begin engaging PWLE in such efforts, especially in areas with scarce resources or infrastructure. This guide provides strategies to integrate PWLE in program development for overdose prevention and offers two example initiatives: overdose spike response and overdose fatality reviews.

This guide is for programs that have not yet engaged PWLE, as well as those programs having significant challenges in doing so. There are five key strategies for including PWLE in overdose prevention and response programs, summarized in Figure 1.

Figure 1. Model for integrating PWLE



Strategy 1: Building rapport

In the initial stages of efforts to involve PWLLE, it is vital to build strong personal rapport with the individuals you are engaging. This is the foundation for establishing and maintaining effective collaboration between agency leadership, staff and PWLLE.

It is important to establish connections early, rather than waiting until the critical moments when the work of PWLLE might be most useful to you. It is hard to establish genuine relationships when the purpose of an interaction is entirely transactional, such as when trying to get information in the short-term to address a crisis event. Establish connections with individuals and organizations separately from needing their input, as part of beginning a longer-term relationship. When starting to build a relationship, be trustworthy and transparent by sharing as much information as you can about the organization you represent, how it works and its aims.

PWLLE come from diverse backgrounds, and it is important to respect their variety of experiences, associated perspectives and understandings of the world. You can deepen rapport with PWLLE by fostering a mutually beneficial relationship and open communication and by demonstrating reliability. For example, you can offer material aid, technical assistance and volunteer labor to organizations led by PWLLE.

Strategy 2: Creating a culture of respect

An organization must undergo shifts in organizational culture, policy and practice to create a culture of respect and inclusion that fosters effective engagement and collaboration with PWLLE. A vital part of this preparation is gaining commitment and buy-in from staff members. The following are some strategies to create a culture of respect where PWLLE can feel comfortable contributing their unique skills and perspectives to achieve shared goals.

1. **Prepare staff.** To ensure that PWLLE can be successfully integrated into a program team, program leaders must prepare existing staff members for working with PWLLE. This preparation includes helping staff to understand why inclusion of PWLLE is important and how their perspectives strengthen overdose prevention and response efforts.

Provide role-appropriate training on stigma, unconscious bias and cultural competence for all team members, as well as training on conflict resolution and leadership. This will increase awareness of potentially stigmatizing or offensive comments and terms, their impact on others, and how to navigate difficult situations effectively.

Solicit trainings from organizations led by PWLLE on relevant topics, such as increasing awareness of stigma and bias related to drug use and PWUD, practicing cultural humility in working with marginalized populations that are disproportionately affected by substance use disorders and overdose, and understanding the challenges that PWLLE face in the workplace and how to support them in navigating these challenges.

2. **Prepare PWLLE to work within your organization.** Develop an orientation process to help PWLLE become acquainted with the program, workgroup or organization's goals, processes and dynamics. Share clear goals and defined processes for their participation and role. This can be a very simple process, with a welcome packet and an introductory meeting for new members. Develop a mentorship program where experienced members guide new members, helping them acclimate to the culture.

3. **Foster open communication.** Encourage open dialogue and active listening during meetings and other interactions. Provide opportunities for everyone to express their perspectives and ideas. Make space for all involved, and be respectful of the courage of PWLLE sharing their perspectives.
4. Implement feedback mechanisms to ensure that individuals can voice concerns, suggestions or grievances without fear of reprisal. Experiment and find what works best for the community and the program, whether that be an anonymous survey or a separate session where concerns are openly addressed.
5. **Promote trust building.** Emphasize respect, trust and confidentiality among team members. Discuss with team members how they all can learn from each other, regardless of background or professional experience and credentials. Organize team-building activities and retreats to foster personal connections and trust-building opportunities outside of regular work settings. These can be simple, such as a meal or recreational activity.
6. **Provide ongoing educational opportunities.** Provide regularly scheduled training sessions and workshops on overdose prevention, trauma-informed care, stigma reduction, harm reduction and cultural sensitivity. Encourage team members and collaborators, including PWLLE, to share their knowledge and expertise, educating others on various topics related to overdose prevention and treatment.
7. **Share information transparently.** Establish clear protocols for sharing information with new members, ensuring that they have access to relevant data, research, reports and other organizational information that is relevant to their work.
8. **Regularly evaluate and adapt.** Conduct periodic team or work group assessments and evaluations to identify areas for improvement and implement necessary changes, giving both existing staff and newly integrated team members an opportunity to provide input.

SIDEBAR: REDUCING STIGMA TO FOSTER A CULTURE OF RESPECT

Stigma is a powerful social force that leads people to label, stereotype and discriminate against others. It undermines a culture of respect. The U.S. Surgeon General has called for a “cultural shift in how we think about addiction” to reduce stigma and improve access to care; this shift is vital for programs that want to integrate PWLLE into their efforts.

There are several strategies to reduce stigma and foster a culture of respect:

- **Pay attention to language.** The language used to describe people who use drugs has a demonstrated impact on how they are treated. Using terms like “addict” or “junkie” perpetuates stigma, while using person-first language that emphasizes the person over their drug use (e.g., “person who uses drugs”) reduces stigma and promotes empathy. Train staff and volunteers in empathy, active listening and nonjudgmental communication.
- **Emphasize the unique experience and expertise of PWLLE.** Emphasize that PWLLE and PWUD have unique knowledge and experiences that make a positive difference in overdose prevention and response efforts. They play an integral role in saving lives.
- **Host stigma reduction training.** Training is important before bringing on PWLLE. Training should begin with a clear explanation of what stigma is, its various forms — such as experienced, anticipated and self-stigma — and its impact. It should cover individual bias, which refers to prejudice toward stigmatized groups, and structural bias, examining organizational policies, practices and culture that contribute to stigma and discrimination. PWLLE should be involved in the development and delivery of the training by co-facilitating sessions and sharing their experiences.
- **Hire staff who are PWLLE.** When done thoughtfully, hiring PWLLE as staff members can reduce individual bias and address structural bias. Involving individuals with lived experience in various roles is a form of social contact, which is known to be one of the most effective strategies for reducing stigma. Working alongside colleagues with lived experience can challenge staff members’ preconceived notions and biases, thereby enhancing their empathy and understanding. (See Strategy 4 for more information on hiring.)

Strategy 3: Promoting an inclusive environment

Effective overdose prevention and response efforts create an inclusive, accountable, equitable space where individuals from varied backgrounds and experiences can come together to achieve common objectives. It is a space in which individuals are responsible for self: their intentions, words and actions. The group has a collective set of principles or guidelines for exchange so that all voices are not just heard but are integral to decision-making processes. And it is an environment where critically reflective thoughts, conversations and actions emphasize equitable inclusion of PWLLE. In inclusive environments, the collaborators:

1. **Actively seek to engage PWLLE from diverse racial, ethnic, socioeconomic, gender identification and professional backgrounds.** This involves outreach to communities often overlooked, addressing barriers to participation.
2. **Develop and communicate guidelines for respectful and inclusive dialogue.** These guidelines should emphasize the importance of maintaining a nonjudgmental environment where everyone feels valued and heard. Make it clear from the start that there will be emotionally challenging conversations that should be navigated with care.
3. **Frame friction and challenges as opportunities to learn and grow together.** Recognize and embrace friction as evidence that multiple ideas are entering the conversation — not that the group is not getting along. Invite individuals with lived and living experience, when they are comfortable, to share how certain comments could make them or others feel.
4. **Establish a confidential reporting mechanism for team members to report offensive or stigmatizing comments and exclusionary behaviors or actions.** This process allows individuals to raise concerns without fear of retribution and ensures appropriate action is taken. If a team member expresses discomfort or offense, the issue can be addressed privately. This enables a personalized response, ensuring the concerns are heard and appropriately addressed.

EXAMPLE: ENGAGING PWLLE IN OVERDOSE SPIKE RESPONSE

Individuals with lived and living experience can provide valuable insights to improve overdose spike response, through focus groups, involvement on committees, outreach or collaboration with organizations that serve PWLLE.

Focus groups. Focus groups and surveys can be conducted among PWLLE to gather their opinions, feedback and suggestions on overdose response plans. Their feedback can help identify gaps in existing plans and develop targeted strategies to address those gaps. Keep in mind that the experiences of PWLLE will often include negative encounters with systems of care. It is important to keep an open mind, honor these experiences and remember that these insights are not personal attacks against you or your organization.

Committee work. PWLLE can be included on planning committees or task forces responsible for identifying overdose hotspots and developing and implementing overdose response plans. PWLLE provide valuable insights and perspectives based on personal and community experiences with overdose. They can assist in interpreting geographic patterns and deepen understanding of root causes and contributing factors of overdose in areas of high need or burden. This information can be used to tailor prevention and harm reduction strategies used in hotspot outreach. PWLLE often can inform programs about what is not evident in officially collected data. For example, during a meeting focused on mapping overdose hotspots and their

link to a hepatitis A outbreak, a participant pointed out an area with community reports of overdose that was being overlooked for outreach efforts. This led to the distribution of naloxone and educational resources in the area, along with the dissemination of an anonymous overdose incident report form to begin to fill in critical gaps in the official data.

Outreach. PWLLE can and should assist in, lead and coordinate outreach efforts, as they have unique insight into how best to reach and support individuals who use drugs. They can promote harm reduction strategies and encourage people to seek help for overdose-related issues. PWLLE who are trained as peer educators or community health workers can help disseminate overdose prevention education, harm reduction strategies and naloxone training to the wider community.

Partnerships. Establishing partnerships with harm reduction agencies, drug user unions or organizations that serve PWLLE can help ensure that the needs and concerns of PWLLE are understood and addressed in overdose spike response. These organizations, such as harm reduction organizations, mutual aid groups or peer-led support groups, can be engaged as partners in the overdose response planning process. These partnerships can be beneficial, since harm reduction organizations have existing infrastructure, processes and rapport for engaging PWUD. Drug user unions often have direct access to information about changes to the illicit drug supply and have informal early warning systems and gatekeepers. However, harm reduction organizations and drug user unions may be distrustful of outside organizations that are seeking access to sensitive data, so it is important to cultivate rapport and emphasize that the common goal is to reduce overdose, rather than to intensify surveillance and criminalization.

Strategy 4: Recruiting, hiring and compensating PWLLE

Often, PWLLE are asked to participate in cross-sector partnerships without proper — or any — compensation. In overdose prevention and response efforts, it is crucial that PWLLE involved in planning, implementation and evaluation are hired as full-time staff members, are paid a competitive wage and receive benefits where applicable and available.

Program coordinators and staff can rely on word of mouth for recruiting PWLLE, such as recommendations and referrals from existing team members or others in the community. They can also recruit from professional circles, such as harm reduction or peer recovery organizations. Drug user unions, organizations that train and certify peer recovery coaches, recovery community organizations and organizations that provide training and credentials for community health workers can also be good venues for recruiting PWLLE.

Staff should prioritize building relationships with key community stakeholders, such as community leaders, advocacy groups, harm reduction coalitions, and health care and treatment providers. This can entail attending community meetings, reaching out for one-on-one discussions and participating in community events related to substance use and prevention. Community leaders often are people with influence in the PWUD community and those in authority at organizations.

Organizations may face challenges when attempting to hire PWLLE, especially around human resources policies related to criminal background checks. Many PWLLE are more likely to have been involved with the legal system in the past, due to the criminalization of substance use through the war on drugs. They must be afforded work opportunities without their background acting as a barrier. While some organizations may prohibit the hiring of people with criminal

histories due to public safety concerns, they are strongly encouraged to conduct individualized reviews of candidates rather than disqualify them based on criminal histories alone. This is especially important because some convictions that automatically disqualify a candidate from employment are based on outdated laws that have since been repealed.

It is critical to make employment as accessible as possible to PWLLE by addressing other common barriers, such as banking; organizations need to be creative in offering accessible forms of compensation to unbanked community members, or in helping them secure a bank account. Another barrier is understanding workplace expectations. PWLLE who may not have held formal employment or worked in the public health field before may need information and guidance on professional norms, coaching on the workplace culture, or training in strengths-based problem-solving as challenges arise during onboarding and early employment.

Finally, drug-free workplace mandates and policies may pose a challenge to hiring PWUD. Organizations subject to such mandates may need to structure the scope of work so PWLLE can be hired as independent contractors and compensated at the market rate for services.

Strategy 5: Collaborating with integrity

Borrowed from the disability rights movement, the slogan “nothing about us without us” has long been adopted by global drug user activist movements. It also was included as one of the guiding principles of the Centers for Disease Control and Prevention’s publication [*Evidence-based Strategies for Preventing Opioid Overdose: What’s Working in the United States*](#). It is more than a call for inclusion: it is a mandate for collaborating with integrity on decision-making, including directly impacted individuals in decisions that affect them.

1. **Give people a seat at the table and give them space to use their voice for change.** Ensure that decision-making bodies have significant representation of directly impacted individuals. This might mean ensuring that a substantial number of seats in policy-making committees, advisory boards or any other decision-making entities are occupied by PWUD, PWLLE and those who have been directly affected by drug policy.
2. **Ensure that PWLLE in decision-making groups have the authority to make a meaningful impact.** Beyond representation, it is essential that PWLLE and others in decision-making groups possess the actual authority and resources to effect meaningful change. This means that PWLLE are not just consultants but have the power to make, implement and enforce decisions. In practical terms, this could involve granting them control over certain budgets or the ability to draft, endorse and amend policies. The key here is that their decisions and recommendations are not merely symbolic but are integrated into actionable strategies of the organization or program.
3. **Ensure that leadership is diverse.** Diverse leadership is more than just including individuals from different demographic backgrounds; it is including many PWLLE from different backgrounds, whose relevant life experiences bring a deeper understanding of the challenges and solutions in each context. Diverse leadership ensures that the decision-making process is enriched with a wide array of perspectives, which bolsters the legitimacy of the leadership.
4. **Foster continuous learning.** Commit to continuous learning and improvement. This means staying informed about the latest research in addiction and overdose prevention and being open to revising practices based on new evidence and the evolving needs of the PWUD community.

5. **Recognize and address the systemic barriers that PWUD face.** Collaboration with integrity also means advocating for policy changes that support harm reduction, access to health care and reducing the impacts of the criminalization of drug use.

EXAMPLE: OVERDOSE FATALITY REVIEW

Overdose fatality reviews (OFRs) are used to identify patterns in overdose fatalities and gaps in overdose prevention through reviews of individual overdose death cases. PWLLE bring unique insights and perspectives to the OFR team. They provide firsthand knowledge of the barriers faced by individuals who use substances and the various factors that may contribute to overdose fatalities. Their inclusion ensures that the review process is truly comprehensive and considers the complexity of factors involved.

Overdose fatality data often seems abstract and detached from the real-life experiences of those affected. PWLLE can offer perspectives that recontextualize the data to gain fresh insights and a new way of understanding. Their presence can help the team question and explore underlying assumptions, consider alternative interpretations and remain focused on which evidence-based interventions and prevention strategies might best serve the individuals and communities affected, given the data.

Including PWLLE on an OFR team recognizes their expertise and acknowledges their essential role in shaping policies and interventions related to substance use disorders. This involvement can empower them to advocate for change and reduce the stigma associated with substance use.

The content and discussions shared in the OFR can be emotional for anyone involved, but this can be especially true for individuals who have experienced an overdose or who have lived or living experience of substance use. However, this should not exclude these individuals from any part of the OFR process to “protect” them from harm. PWLLE can safely participate in and bring valuable insights to all aspects of the OFR, including aggregate data review, individual case review and issuing recommendations.

Key strategies for how to promote an inclusive environment and create a space for safe discussions within an OFR team align with those emphasized above in Strategy 2. In particular, OFR teams should:

- Establish clear guidelines to help maintain a safe and nonjudgmental environment, setting aside time in meetings to address charged issues head-on if needed.
- Review and screen materials and data before each meeting, to identify those that contain stigmatizing or offensive comments. This proactive approach can help teams decide to remove those materials from the review or prepare to acknowledge and address the material during the discussions.
- Set a positive tone at the beginning of each meeting to encourage open and honest dialogue. Emphasize the importance of respectful communication, and invite team members to raise concerns about offensive or stigmatizing comments as they happen.
- Use active facilitation skills to guide the conversation. Intervene when necessary to shift the conversation in a more constructive and inclusive direction. Frame comments as learning opportunities, providing education on the impact of such comments and helping team members learn and grow together.

- When inappropriate or stigmatizing comments occur, remind the team of the purpose of the OFR and how stigmatizing language can distract from that aim. When challenging conversations get off track, remind the team of the objectives of the conversation and that including and addressing different perspectives are vital to the review process.
- Evaluate and adapt the processes surrounding team meetings. Solicit feedback from team members to identify and openly discuss areas for improvement and implement changes accordingly.

By implementing these strategies, the program team can foster a welcoming environment, build trust, share information and remain inclusive of individuals with lived experience, ultimately enhancing its effectiveness in addressing and preventing overdose fatalities.

Conclusion

The inclusion of PWLLE in overdose prevention and response programming can provide a unique and valuable perspective, making programs more relevant and effective for those served. While there may be initial challenges in relationship-building, changing organizational culture, recruitment and onboarding, PWLLE can be successfully integrated into programs with the right shifts in organizational and program culture. This collaborative approach — where all affected community members, including PWLLE and PWUD, can contribute their knowledge and skills to better address the overdose crisis — can lead to more effective solutions to this complex issue, improving community relations and ultimately reducing overdose.