



Voices of Lived Experience: Meaningful Engagement and Effective Uses of Opioid Settlement Funds

Webinar Key Takeaways

Quick Takeaways:

- Lived experience with substance use and substance use disorder is wide ranging and diverse.
- Those with lived experience are critical to planning and decision-making efforts.
- Creating trust and safety are key facets of working with the population with lived experience.
- Community-based organizations, such as harm reduction providers and recovery community organizations, can be key partners in creating meaningful engagement with those with lived experience.

WEBINAR HOSTED BY THE MICHIGAN ASSOCIATION OF COUNTIES IN PARTNERSHIP WITH THE MICHIGAN OVERDOSE PREVENTION COALITION, MICHIGAN ASSOCIATION OF RECOVERY COMMUNITY ORGANIZATIONS, MICHIGAN OPIOID ADVISORY COMMISSION AND MICHIGAN DEPARTMENT OF HEALTH AND HUMAN SERVICES

DEFINING LIVED EXPERIENCE

- Someone who has been through the experience of substance use or substance use disorder and knows the complexities of dealing with it and the real-life solutions for dealing with it.
- Diversity of lived experiences:
 - No two people with substance use experience have experienced the same thing; it is important to keep an open mind to other experiences and be inclusive.
 - Lived experience with substance use and lived experience with substance use disorder:
 - It is important to understand that people move through substance use in a non-linear way and substance use occurs on a spectrum.
 - There is a wide variety of experiences and needs.
 - Some individuals who have substance use experience do not have or do not identify as having a substance use disorder:
 - Individuals may have the same needs but may not access services due to not identifying as someone who would typically seek those services.
 - How an individual identifies may impact their own awareness of what their needs are.
 - To create meaningful programs for and results on the drug overdose crisis, the perspectives of those with personal experience with substance use are critical.
- Importance of representation:
 - “Stigma dies in the light.”
 - When those with lived experience are at the table, this creates a space where everyone feels heard and everyone can access support.
 - There is a practical necessity to include those with lived experience to develop the best possible services based on experiential knowledge.
 - There is an ethical responsibility to include those with lived experience to ensure any programs or services developed for those impacted by substance use are also informed and supported by those with lived experience.

BROADER DEFINITIONS

- **Recovery:**
 - There are numerous definitions of recovery, and the experience of recovery is personal and unique.
 - One definition: “Recovery is any positive change as a person sees it for themselves.”
 - What recovery means may change to an individual as different points in their recovery journey.
- **Harm Reduction:**
 - The National Harm Reduction Coalition defines harm reduction as “a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use. Harm Reduction is also a movement for social justice built on a belief in, and respect for, the rights of people who use drugs.”
 - Harm reduction is about meeting people where they are at.
- **Syringe Service Program:**
 - Risk or harm reduction programs provide individuals who are engaged in substance use the necessary items and support to reduce the harms associated with drug use, including transmission of communicable diseases and overdose. (Items may include naloxone, fentanyl test strips, syringes, pipes and straws, among others). (Supports may include connection to a formal health care or behavioral health professional, including peer support.)
- **Co-occurring Disorders:**
 - Having a substance use disorder and a mental health disorder at the same time.
- **Equity:**
 - Recognizing the unique differences and needs in individuals and communities (geographic, social, cultural, economic, etc.) and the impacts of those differences.
- **Safety and Community Connection:**
 - Creating spaces intentionally where individuals can be heard and feel comfort.
 - Strategies to create safety include an authentic commitment to caring, compassion, learning, partnering, listening, being empathic to other experiences and open mindedness.
 - “The opposite of addiction is human connection.”

WHY IS IT CRITICAL TO ENGAGE WITH INDIVIDUALS WITH LIVED EXPERIENCE?

- Those with lived experience are the minority in the policy and program development spaces. Programs and policies often are not designed by the people they are intended to serve.
 - This can lead to many aspects of programming and policy being overlooked.
 - Program and policy work require an understanding of the unique needs of the community to understand where gaps are and where process improvements are needed.
 - For programs to be effective, they must be utilized.

BARRIERS TO ENGAGING INDIVIDUALS WITH LIVED EXPERIENCE

- Criminalization:
 - Substance use disorder, except for HIV and sometimes pregnancy [and sometimes mental health conditions], is the only criminalized medical condition.
 - Criminalization causes lack of trust with service providers and reduces opportunities for engagement.
 - There are numerous resources that are not eligible to those convictions associated with drugs, including Free Application for Federal Student Aid (FAFSA) loans, Section 8 housing, Temporary Assistance for Needy Families (TANF), etc.
- Lack of information or access to individuals with lived experience:
 - Take actionable steps in learning about lived experience, ways to engage those with lived experience and how to be a supportive partner.
- Lack of trust:
 - To foster trust, a commitment to empathy, partnering, listening, and humility is critical. It is important to understand where there have been current and historic harms.
 - Listen to those with lived experience on what steps can be taken to engage in meaningful support and engagement.

STRIKING THE BALANCE OF REPRESENTATION AND AVOIDING TOKENISM

- To get the most inclusive perspective, continue to sample and listen to those with lived experience. Focus on creating ongoing and intentional efforts to engage. Let those with lived experience guide engagement efforts. Ask those with lived experience who is missing from the table.
- Best practice is to provide compensation for individuals sharing their time and expertise.
- Consider how often individuals can be offered opportunities to be heard. Consider the locations and times for these opportunities. Consider unique differences and experiences in planning efforts and create a safe and equitable space.
- Remember that vulnerability is at the center of sharing personal experience with substance use.

Recovery Capital

Resources for Achieving and Maintaining Recovery

Personal

- Skills and tools
- Finances
- Education
- Housing
- Health and healthcare
- Purpose in life

Family and Social

- Relationships with friends, family, and people in recovery
- Recovery-friendly activities and events

Community

- Advocacy/policy
- Stigma
- Peer Support
- Recovery Housing
- Treatment and Recovery Resources

Cultural

- Spiritual
- Faith-based

PRACTICAL STEPS TO ENGAGE INDIVIDUALS WITH LIVED EXPERIENCE

- Visit community-based organizations like Recovery Community Organizations and Syringe Service Programs to better understand the services provided and the needs of those they serve.
- Leverage relationships with community-based organizations to increase engagement with individuals who can share their experiences and the gaps and barriers to accessing services.
- Consider making those with lived experience the majority, not the minority, in planning and decision-making efforts.
- Create an authentic and honest commitment to caring and learning.
- Do not politicize or tokenize those with lived experience with substance use and substance use disorder.
- Seek out opportunities for education and support, such as utilizing technical assistance resources available both locally and nationally:
 - Michigan Department of Health and Human Services
 - Opioid Advisory Commission
 - Michigan Overdose Prevention Coalition
 - Michigan Association of Recovery Community Organizations