



# MEANINGFUL INVOLVEMENT OF PEOPLE WHO USE DRUGS

*NOTHING ABOUT US WITHOUT US*

Meaningful involvement of people who use drugs ensures the leadership and decision-making power of people with lived experience of drug use in the response to the intersecting crises of drug use, viral hepatitis, and HIV.

The principle of meaningful involvement of people who use drugs is one of the core principles of harm reduction.<sup>1</sup> It was first articulated by the Rotterdam Junkie Union in the Netherlands in 1977 and reinforced by a global community of people who use drugs in the Vancouver Declaration in 2006. It is closely linked to the “nothing about us without us” ethic of the Denver Principles, which outline the meaningful involvement of people living with HIV.<sup>2</sup> Meaningful involvement is also supported by Centers for Disease Control and Prevention, which has acknowledged that overdose prevention strategies must involve those most at risk for overdose.<sup>3</sup>

## WHY MEANINGFUL INVOLVEMENT?

People who use drugs are intimately familiar with their communities’ needs, cultures, and barriers to services and health. Their expertise is essential to building effective services and trusted spaces where people who use drugs can access services and be treated with respect and dignity.

Meaningful involvement of people who use drugs can increase support for harm reduction policy and advocacy efforts; challenge myths related to drug use, HIV, and viral hepatitis; and reframe the narrative supporting criminalization. Opportunities for job training and employment are in themselves an important component of harm reduction in communities of people who use drugs. In fact, hiring people with prior convictions lowers rates of unemployment, crime, and recidivism.<sup>4</sup>

## MECHANISMS FOR INVOLVEMENT

People who use drugs have the capacity to educate and be educated; form organizations; manage funding; serve in consultations, decision making, policy making and advisory structures; and be employed in a variety of roles.<sup>5</sup> Yet people who use drugs face many challenges that restrict their ability to engage with public health professionals and policy makers, including persistently high levels of stigma and discrimination.<sup>6</sup>

Support for people who use drugs and their organizations must include explicit recognition of their unique value and perspective by both public health agencies and local governments. It must also include capacity building support and financial backing for innovative projects and programs that embody the principles of meaningful involvement.

Organizational policies and practices may need to be reconceptualized, or overhauled completely, in order to meaningfully involve people who use or formerly used drugs, people affected by police surveillance and the criminal-legal system, young people, people of trans experience, and people of color.

*PEOPLE WHO USE DRUGS MUST BE ENGAGED IN SHAPING POLICY AGENDAS AND SHIFTING SOCIAL ATTITUDES TOWARD THEIR OWN COMMUNITIES.*



## Meaningful Involvement of People Who Use Drugs Self-Assessment

### Ask yourself...

#### Input and Engagement

- Do you compensate people who use drugs for their participation in meetings and advisory boards?
- Do you offer training and support for people who use drugs?
- How do you include people who use drugs in your services, consultative processes, advisory boards, and research?
- Do you involve people who use drugs in program development and evaluation?

#### In the Workplace

- What policies exist around hiring and recruiting people who use drugs and/or with an arrest or criminal record?
- How are work-related problems for employees who use drugs resolved?
- To what extent are job advancements made available to employees who use drugs?
- How does organizational leadership reflect the communities you serve?

#### In the Movement for Social Justice

- Have you engaged in workshops to reduce drug-related stigma and discrimination? Do you share such resources with others?
- How do you support organizations or coalitions of people who use drugs and syringe services programs in your region?

# MEANINGFUL INVOLVEMENT OF PEOPLE WHO USE DRUGS

Community-based organizations should involve people who use drugs at all levels to identify, develop, implement, and evaluate interventions necessary to reduce harm associated with drug use, including opioid overdose education and naloxone distribution, safer drug use interventions and education, and support meetings.

Listed below are practices that can be put in place to reinforce meaningful involvement of people who use drugs.

## HIRE PEOPLE WHO USE DRUGS



### DO:

- ✔ Learn about harm reduction policies for the workplace.<sup>7</sup>
- ✔ Focus on workforce development and provide trainings and employment opportunities, or partner with an organization that does.
- ✔ Communicate with organizations of people who use drugs about the barriers and challenges they face and act on opportunities to partner, share resources, and compensate them for their efforts.

### DO NOT:

- ✘ Impose a blanket ban on employees with an arrest or criminal record.
- ✘ Overlook a frontline employee, like a peer outreach worker, for career promotion.

## HOLD ACCOMMODATING MEETINGS



### DO:

- ✔ Be flexible about meeting times, location, agenda, and level of participation.
- ✔ Prepare new attendees with training and a support person.
- ✔ Learn from people who use drugs how to make the meeting more inclusive.
- ✔ Acknowledge gaps in your own experience and address any discomfort or unfamiliarity openly and respectfully.

### DO NOT:

- ✘ Put the burden of preparing for and integrating into meetings on people who use drugs.
- ✘ Assume that you cannot learn how to integrate people who use drugs into your meetings.



## INVITE PEOPLE WHO USE DRUGS TO THE TABLE

### DO:

- ✔ Invite several people who use drugs – not just one – to meetings.
- ✔ Share who else will be attending – especially when meetings include law enforcement, parole officers, or city officials – and how people who use drugs are expected to contribute.
- ✔ Designate a minimum percentage of seats on an advisory board or in organizational leadership for people who use drugs.
- ✔ Guarantee and protect confidentiality and ask about preferred contact methods.
- ✔ Provide financial support for participation in meetings, such as travel stipends, honoraria, and per diems.
- ✔ If travel is involved, help arrange identification, credit cards, and healthcare, especially access to medication-assisted treatment.

### DO NOT:

- ✘ Require disclosure of personal information, such as HIV, health status, or exposure to trauma.
- ✘ Tokenize people who use drugs.
- ✘ Invite only people who formerly used drugs or the same person you are comfortable with every time.



## ADDITIONAL RESOURCES

Access free resources, training, and technical assistance @ [aidsunited.org](https://aidsunited.org)



<sup>1</sup>) Harm Reduction Coalition (2018). Principles of Harm Reduction. Available at: <https://harmreduction.org/about-us/principles-of-harm-reduction> <sup>2</sup>) AIDS United, The US People Living with HIV Caucus (2017). Meaningful Involvement of People with HIV/AIDS. Available at: <https://www.aidsunited.org/resources> <sup>3</sup>) Centers for Disease Control and Prevention (2018). Evidence-Based Strategies for Preventing Opioid Overdose: What's Working in the United States. Available at: <https://www.cdc.gov/drugoverdose/pdf/pubs/2018-evidence-based-strategies.pdf> <sup>4</sup>) National Employment Law Project, Safer Foundation (2016). A Healthcare Employer Guide to Hiring People with Arrest and Conviction Records: Seizing the Opportunity to Tap a Large, Diverse Workforce. 2016. Available at <https://www.nelp.org/wp-content/uploads/NELP-Safer-Toolkit-Healthcare-Employer-Guide-Hiring-People-with-Arrest-Conviction-Records.pdf> <sup>5</sup>) Canadian HIV/AIDS Legal Network, the Open Society Institute Public Health Program, and the International HIV/AIDS Alliance (2008). Nothing About Us Without Us: A manifesto by people who use illegal drugs. Available at: <https://www.opensocietyfoundations.org/reports/nothing-about-us-without-us> <sup>6</sup>) Ti, L., Tzemis, D., & Buxton, J. A. (2012). Engaging people who use drugs in policy and program development: A review of the literature. Substance Abuse Treatment, Prevention, and Policy, 7, 47. <sup>7</sup>) Open Society Foundations (2010). Harm Reduction at Work: A Guide for Organizations Employing People Who Use Drugs. Available at: <https://www.opensocietyfoundations.org/reports/harm-reduction-work>