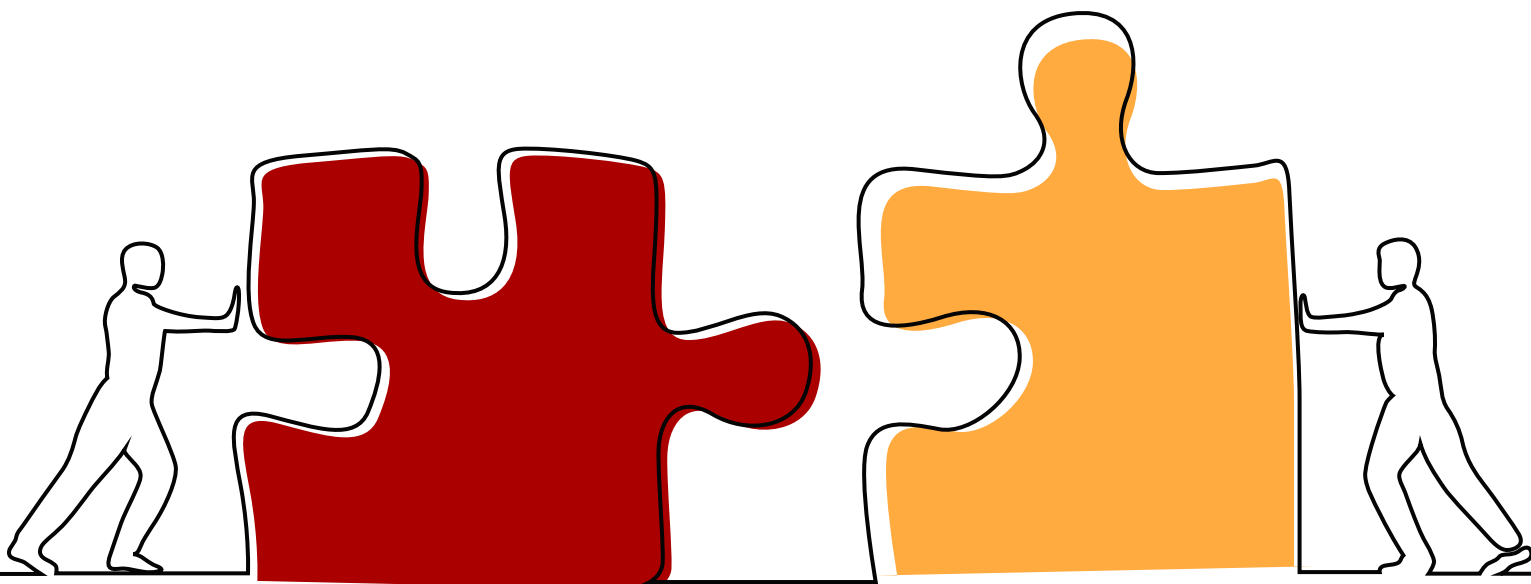




STATE STRATEGIES IN ACTION:

FACILITATING EQUITABLE PARTNERSHIPS WITH PEOPLE WITH LIVED EXPERIENCE



The Health Resources and Services Administration (HRSA)-funded Ryan White HIV/AIDS Program Special Projects of National Significance (SPNS) initiative Strengthening Systems of Care for People with HIV and Opioid Use Disorder (OUD) provides coordinated technical assistance across HIV and behavioral health/substance use service providers. The project aims to enhance system-level coordination and networks of care among Ryan White HIV/AIDS Program recipients and other federal, state, and local entities. The purpose of this initiative is to ensure that people with HIV and OUD have access to care, treatment, and recovery services that are client-centered and culturally responsive.

SSC developed this resource in response to the needs of the nine state partners participating in the project. For more information about the project and to access additional resources, visit <https://ssc.jsi.com/>.

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This resource is part of the State Strategies into Action series; a compilation of strategies and lessons about a variety of topics related to strengthening systems of care for people with HIV and opioid use disorder (OUD). Each resource responds to common technical assistance (TA) needs identified across states partnering with JSI Research & Training Institute, Inc. as part of the [Strengthening Systems of Care for People with HIV and Opioid Use Disorder](#) (SSC) project.

INTRODUCTION

This resource describes how state health departments and other public health organizations can partner with people with HIV and/or who use(d) drugs in programmatic and policy making processes and evaluation. When guided by equity and inclusion, organizations can support “people with lived experience to act as leaders in reducing barriers and bridging communities, services, and policies.”¹

This resource includes:

- examples of how Rhode Island (RI) and Iowa (IA) have involved people with lived experience in HIV and substance use disorder (SUD) programmatic and policy making processes;
- recommendations for engaging and partnering with people with lived experience; and
- special considerations when involving people with HIV and/or who use(d) drugs.

The authors acknowledge that some of the strategies presented in this resource may not be applicable in every context. This document spotlights inspiring examples in the field and communicates guiding principles to consider when involving people with lived experience, all of which should be adapted and tailored to the local context.

DEFINITIONS OF TERMS

While there are many definitions for the terms “lived experience” and “trauma-informed approach,” this resource uses the following definitions:

Lived experience: People who have gained knowledge through direct, first-hand involvement in everyday events, rather than through assumptions and constructs from other people, research, or media.²

Trauma-informed approach: An approach that “realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeking to actively resist re-traumatization.”⁴

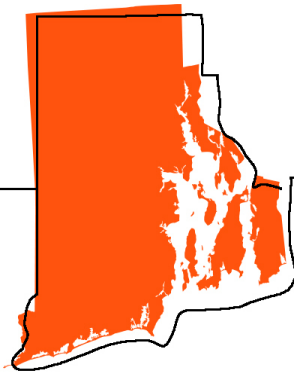
Individual trauma results from an event, series of events, or circumstances that a person experiences as physically or emotionally harmful and that has lasting adverse effects on the person’s ability to function as well as their mental, physical, social, emotional, and/or spiritual well-being.⁴

A trauma-informed approach has six key principles, which are further explained in [guidance](#) from the Substance Abuse and Mental Health Services Administration (SAMHSA):

1. Safety;
2. Trustworthiness and transparency;
3. Peer support;
4. Collaboration and mutuality;
5. Empowerment, voice, and choice; and
6. Cultural, historical, and gender issues.

STATE EXAMPLES

RI and IA state health departments shared their efforts in partnering with people with lived experience in their programmatic and policy making processes, specifically related to HIV and opioid use disorder (OUD) service delivery. Their efforts are described below and throughout the resource using 🗨️ “advice from the field” call-out boxes.



Rhode Island

The Ryan White HIV/AIDS Program (RWHAP) provides primary medical care and support services for people with HIV who are uninsured or underinsured. RWHAP Part B funds states and territories to improve HIV health care and support services. RWHAP recipients also engage people with HIV and other community members in ongoing planning processes to guide jurisdictional activities.⁵

The **RI RWHAP Part B Community Advisory Board (CAB)** is a group of 20 people with HIV who advise the RI Executive Office of Health & Human Services and HIV Provisions of Care Program on issues affecting the lives of people with and at risk of HIV.⁶

In order to meet the RI RWHAP Part B requirements to maintain 20 members, the CAB recruits members as needed by sharing membership opportunities with its networks and working with case managers at collaborating agencies to disseminate information and the application form. Applicants are interviewed at CAB meetings, after which current members make selections.

The health department contracts with external facilitators to work with a co-chair (a nominated member of the CAB) to ensure that members have multiple ways of providing input and sharing information. This includes reserving agenda time for a check in and announcements and providing opportunities for CAB members to share ideas and resources via email. The CAB’s meetings are not open to the public; therefore, CAB membership determines who can attend to present, listen-in, or ask for input. They also vote on recruitment, meeting goals and location, officials, and whether to pursue various activities (e.g., coordinating a conference, having a presence at various events).

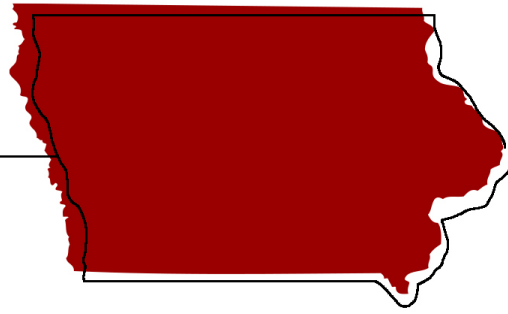
Facilitators provide meals at each in-person meeting and co-create guidelines for how meetings are conducted. This includes asking for feedback at the end of the meeting through a form and responding to it at the next meeting, all while compensating members for their time. State employees collaborate with the CAB members to allocate their budget. CAB members review the CAB budget on a consistent basis and provide input on budgetary decisions. State employees ensure that the CAB budget is prioritized and never reduced. In addition, the CAB conducts an initial round of feedback on surveys for the state’s HIV needs assessment.

Facilitators shared that state leadership must be committed to transparency and to processes that incorporate CAB input in decision making. To this end, RI RWHAP Part B staff respect CAB autonomy and accept all CAB decisions as final.



“It is their space and we honor that space”

- RI CAB facilitator



Iowa

Iowa’s Health Initiative for People Who Use Drugs (HIPWUD) formed in 2018 as an advisory group to Iowa’s Department of Public Health. It comprises multi-sector professionals and people who use(d) drugs and focuses on improving the “health and well-being of people who use drugs.”⁷

Some of the many challenges to meaningful community engagement in IA have been the illegality of syringe services programs; staff and funding constraints; and lack of trust of the health department among people who use(d) drugs. To overcome these challenges, HIPWUD worked with harm reduction centers and related networks to leverage trusted relationships and identify people who use(d) drugs to participate in the group.

HIPWUD’s coordinator identified grant funding to pay people who use(d) drugs for their time and invited them to participate in key informant interviews (KIIs). Their participation in the KIIs facilitated relationship building and information gathering for harm reduction message development and education.

In preparation for the KIIs, the coordinator created training materials on how to interview people with lived experience, researched incentive restrictions, and developed a thorough consent form with details on how the information gathered would (and would not) be used.

The connection with harm reduction centers and the KIIs led to more visibility for HIPWUD at the state and community levels. HIPWUD continues to identify and work with harm reduction partners on opportunities to engage and build trust with people who use(d) drugs. The HIPWUD coordinator said that to value the expertise of and create positions of power for people who use(d) drugs, it is essential to post job positions that do not have formal degree requirements or academic achievements. The coordinator emphasized that those in power must be willing to champion these efforts.

IA and RI’s engagement activities exemplify joint planning approaches (see Figure 1, Page 8) that involve people with lived experience alongside state employees, local community-based organizations, and service providers.

CONSIDERATIONS FOR STATE ACTION

Conversations with state partners and a review of selected literature informed the key considerations below for state action when involving people with lived experience.

Identify the “Why” for Your Organization

Working with people with lived experience requires time and flexibility. Therefore, it is important to gain team members’ buy-in, build momentum, and understand your organization’s motivation for involving people with lived experience. Some examples of “why” include facilitating the ability to:^{1, 8, 9}

- **Bridge community needs with service delivery and policy.** People’s needs are context specific and change constantly. Staff need to be aware of what is happening in the communities they serve. People with lived experience can provide this information and identify community priorities.
- **Promote sustainability.** People who are directly affected are more likely than professionals who lack personal experience to stay committed to a specific issue because their lives and those of the people they care about depend on it.
- **Increase individuals’ ownership of their health.** Involving people with lived experience is key to shifting the historical power imbalance between people who make and those who are affected by service, policy, and system decisions. Equitable partnership can increase the relative control people have over their lives, communities, and health outcomes. The phrase ‘Nothing about us without us’ makes clear the need for community members’ “full and direct participation in all decisions” that affect their lives.^{8, 9}
- **Shift internal perceptions and catalyze social change.** Over time, continued dedication to fostering equity, sharing power, and building trust can support a sense of belonging and a more democratic and participatory decision-making process. This, in turn, can change perceptions of people with lived experience in organizations and catalyze further social action.¹



It’s a two-way street. IA’s HIPWUD said, “We can learn from them and they can learn from us.”

It’s not simply checking the box. RI CAB emphasized that engagement is “labor intensive” and to do it effectively, health departments have to be authentic and not simply see it as checking a box. “People have to believe it philosophically.”



Question for consideration:

What are your organization’s motivations for engaging people with lived experience?

Structuring the Level of Engagement

Organizations can consider various levels of engagement for people with lived experience.

- If an organization is new to this work, start with lower levels of engagement (see Figure 1, Page 8) to build relationships and collaboration. This will increase people’s willingness to be involved.
 - Consider developing a plan for how your organization will increase engagement.
 - Keep in mind that the goal is to move from [tokenism](#) (e.g., filling a designated slot) to engagement in which individuals contribute their knowledge, skills, and experience.
- Regardless of the level of engagement:
 - Be transparent and clear about what is expected of those involved so that people know what they are signing up for.
 - Follow up with individuals that have engaged with your organization to tell them how their input was used and to provide opportunities for ongoing input.
 - Ensure that people with lived experience are treated equally to other team members (i.e., have the same level of input, decision-making ability, and access to organizational resources).

FIGURE 1. LEVELS OF ENGAGEMENT FOR INVOLVING PEOPLE WITH LIVED EXPERIENCE ^{16, 17}

	LEVEL OF ENGAGEMENT	TOOLS FOR ENGAGEMENT	DESCRIPTION
<p>MORE SUSTAINABLE</p> <p>MORE AUTONOMY</p> <p>MORE COMMUNITY PARTICIPATION</p> <p>BUILDS MORE CAPACITY</p> <p>OFTEN FEWER PARTICIPANTS</p> <p>↑</p> <p>↓</p> <p>LESS AUTONOMY</p> <p>LESS COMMUNITY PARTICIPATION</p> <p>BUILDS LESS CAPACITY</p> <p>OFTEN MORE PARTICIPANTS</p>	Community directed	Organizational leadership	Staff apply their lived experience to oversee the direction, scope, and strategic plans of an organization.
	Acting together	Staff	Employees apply lived experience to influence, implement, develop, and/or direct departmental work across programs and/or services.
	Joint planning	Partnership	Health departments facilitate ongoing communication and work together with people on an initiative or project.
		Advisory leadership	People with lived experience participate in leadership groups, such as project committees and advisory boards.
	Consultation	Consulting	Health departments gain in-depth and focused information through ongoing interactions with people with lived experience.
	Sharing information	Interviews, surveys, focus groups	Health departments gather information, generally in one encounter, to understand a lived experience perspective and/or gain input on specific issues or efforts.



Questions for consideration: Looking at the chart above, where do your organization’s activities fall? What opportunities exist to increase involvement in decision making processes for people with lived experience?



Give people power. IA HIPWUD ensures that staff value experience the same way traditional education is valued. They encourage staff to think about ways to increase involvement in decision making processes for people with lived experience, which may include starting with interviews.

RECOGNIZE AND REMOVE BARRIERS

Many barriers to the involvement of people with lived experience are a result of historical and current structures of discrimination, racism, and prejudice. Two barriers and potential strategies to overcome them are described below.^{10,11}

1. Lack of access

People often find it challenging to make time for activities in addition to their jobs, families, and other responsibilities. Additionally, some lack or have limited access to phones, technology, housing, and transportation. Organizations should make participation as accessible as possible.

Strategies to address lack of access:

- **Identify accessible locations and modalities.** Make meeting places safe, convenient, close to public transportation, and accessible to people with disabilities or who require accommodations.^{10,11} If meeting remotely, provide—or compensate for—access to resources like internet, phone, and tablets/computers.
- **Ensure fair compensation.** Compensate people fairly to demonstrate respect for their time and expertise. Compensation should never be presented as contingent upon participants' opinions or as a tool to influence decisions.
 - Research what is allowable for your organization and create payment infrastructure prior to involving people with lived experience. If you are unable to compensate monetarily, ask people how they would like to be compensated, and respond accordingly. Some important questions to consider are:
 - Can you pay in cash?
 - Will there be an hourly rate or a stipend? If yes, how much?
 - How will payments be distributed?
 - Provide compensation that reflects what paid staff receive for similar work.
 - Be clear about payment and any implications it may have on other compensation or benefits people receive.



Get creative and start early. Due to constraints in using federal funding to compensate people who use(d) drugs for their time and input, IA HIPWUD utilized alternative grant funding to compensate people for participating in HIPWUD activities (e.g., KIIs). HIPWUD recommends starting conversations about compensation early in the planning process.


Pay for all activities. RI CAB members are paid to complete additional activities outside of participation in meetings. CAB members are consultants and receive compensation accordingly.

2. Distrust, stigma, and tokenism

People are often stigmatized and [tokenized](#) because of their identities (e.g., sexual orientation, gender identity) and experiences (e.g., using drugs, living with HIV, engaging in sex work). They may fear further marginalization or harm if they engage in state-sponsored efforts.¹⁰ People who partake in activities classified as illegal and speak about it publicly may put themselves at significant risk.

Strategies to help avoid distrust, stigma, and tokenism:

- **Ensure leadership buy-in and support.** Without organizational leadership buy-in, support, and the allocation of resources, engagement opportunities will feel insincere and tokenizing. Individuals who feel this will distance themselves further from the system.
- **Be clear about expectations.** When reaching out to people with lived experience, be explicit about the level of engagement and expectations.
 - Clearly outline the negotiation, engagement, and agreement processes.
 - Specify how their input will be used (e.g., resource allocations, policy decisions).
 - Set up consistent engagement opportunities.




Avoid making promises you can't keep. IA HIPWUD emphasized the need to be transparent when communicating with people about the processes and outcomes.

Ensure that people understand the compensation process and how their input will be used.

Keep agendas and meetings consistent. RI CAB facilitators keep agendas consistent and send them out weeks in advance. Meetings begin and end on time and are not canceled. The structure fosters a sense of safety and trust in leadership.

When in doubt, ask. IA noted the principle of asking individuals if and how they want to be involved.


- **Ensure confidentiality and transparency.** Be transparent about all aspects of engagement while maintaining confidentiality. If the identities of individuals with lived experience will be shared with funders (e.g., Centers for Disease Control, HRSA, SAMHSA), let them know ahead of time. Keep participant lists confidential and inform individuals who will have access to them.
 - Review your duty as a health department to post meeting minutes or attendance lists. If public posting is required, post only first names and roles (e.g., co-chair, note-taker) for all members.
 - Do not reveal a person's HIV status or current/past substance use without that person's explicit permission.



Practice transparency. RI CAB members review the budget on a consistent basis and provide input on budgetary decisions.

Ensure confidentiality again and again. IA HIPWUD repeatedly revisits confidentiality and transparency to make sure that individuals are represented in the ways they want to be.

- **Acknowledge the whole person.** Do not overemphasize people's experiences or overlook their skills and other contributions.
 - Ask people what they are interested in (beyond the topic that brought them to participate).
 - Listen to their concerns and preferences.
 - Offer opportunities for professional growth.
- **Recognize diversity, intersectionality, and inclusivity.** Never ask an individual to speak on behalf of an entire community of which they are a member. Ensure that the people you engage reflect the diversity of identities and experiences within communities. This includes people of different ages, gender identities, sexual orientations, races, ethnicities, and abilities, as well as people with newly diagnosed HIV and long-term survivors.
- **Work with existing networks.** Take time to build trust with community partners based on authentic relationships, not transactions. Engaging with existing peer-based organizations and networks can increase trust and facilitate access to information and perspectives.



Partner with existing networks. IA HIPWUD partnered with housing, treatment, and underground syringe services providers to interview people who use(d) drugs. Respect the work that existing organizations have done with the communities you are trying to reach.

- **Demonstrate humility.** Never assume you know more than the people with whom you work. Learn about a person’s or organization’s history before you start working together.
 - Ask questions that will inform your practices, programs, and/or policies.
 - Ask people how they want others to refer to them.
- **Support capacity building and growth.** When people with lived experience participate in service planning and policy-making, they build skills that may lead to professional work in the field.
 - Model capacity building strategies by providing onboarding materials, explaining industry jargon and acronyms, and offering training on data, meeting facilitation, and participation skills.
 - Advocate for minimal jargon and reconsider standard business norms (e.g., hours of operation, dress code) to make workplaces more welcoming.



Questions for consideration: What are some barriers people may face when working with your organization? What strategies will help mitigate these barriers?

SPECIAL CONSIDERATIONS FOR ENGAGING PEOPLE WITH HIV

From the earliest days of the epidemic, people with HIV have exercised their rights to be heard and to shape the systems that serve them. Organizations should be aware of this history of self-determination and community direction, and leverage structures that include the voices of people with HIV, such as:

RWHAP Part A planning councils/bodies

The federal legislation authorizing the RWHAP requires the establishment of planning councils/bodies in the 52 metropolitan jurisdictions that it funds.¹³ By law, at least 33% of planning council/body members must be people with HIV who live in the jurisdiction and use RWHAP services. Planning councils/bodies make decisions about the allocation of RWHAP Part A program funds.

Community advisory boards

Community advisory boards at HIV service organizations, health centers, and clinics provide input and guidance on design and delivery of care.

The 1983 Denver Principles ¹² recommend that “people with AIDS”:	When partnering with people with HIV organizations can...
1. “Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.”	1. Develop mechanisms for people with HIV to determine the services, supports, and resources that their communities need. Give them the space to set the agenda and determine the priorities when possible.
2. “Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.”	2. Continually examine the level of engagement being offered to people with HIV. Strategize about how the organization can move to greater levels of partnership and direction.
3. “Be included in all AIDS forums with equal credibility as other participants , to share their own experiences and knowledge.”	3. Ensure equal respect, power, access to resources, and credibility as other staff and collaborators working alongside people with HIV.
4. “Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.”	4. Support the provision of harm reduction services and invest in community directed initiatives to reduce harms for people with HIV and people who use(d) drugs.

SPECIAL CONSIDERATIONS FOR ENGAGING PEOPLE WHO USE(D) DRUGS

People who use(d) drugs in the United States experience significant trauma, criminalization, and discrimination. Many have distrust in systems, including public health and health care. Effective support for people who use(d) drugs, however, cannot succeed without their meaningful engagement.¹⁴ Before engaging people who use(d) drugs, an organization must first:

- **Set parameters for current or past drug use.** Due to the criminalization of drug use in most communities, an organization must plan carefully to keep the identity of people who use(d) drugs confidential and protect their privacy.
 - If it is not feasible for an organization to engage people who actively use drugs safely, solutions may include:
 - Using a lower level of engagement (such as focus groups and KIIs) to gather their perspectives in a safer space; and/or working with people in early but stable recovery.
NOTE: individuals in early recovery have a valuable perspective but may not feel comfortable speculating on the needs of people who are actively using drugs.
- **Think critically about when and how to engage individuals across various sectors to avoid re-traumatization and harm.** Organizations often seek to form large multidisciplinary groups that may inadvertently ask people who use(d) drugs to work alongside those who may have imprisoned, criminalized, or otherwise harmed them.
 - Use a trauma-informed approach to ensure that people are neither re-traumatized nor triggered. Always provide an option for people to opt-out.
 - Do not work with law enforcement when trying to engage people who use(d) drugs. While the perspectives of both groups are important to inform your work, they do not need to be involved at the same place and time.
- **Train all team members to work with people who use(d) drugs.** Engage individuals who represent these groups to lead or be otherwise involved in the training. Topics may include:
 - understanding substance use disorders as both a learned set of behaviors in response to trauma and environmental conditions, and as a disease;¹⁵
 - de-stigmatizing language;
 - harm reduction principles; and
 - the history of the criminalization of drug use in the United States.



Only ask for the information you need. Instead of asking about the exact details of drug use in their KII consent form, IA HIWUD asked whether an individual had used substances in the last 12–18 months to inform whether they should make different groups for those in self-defined recovery and those not.

ADDITIONAL RESOURCES

While this guide provides general considerations for facilitating equitable partnerships with people with lived experience, other organizations have developed comprehensive and in-depth materials to operationalize these practices:

- [Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends](#)
- [Best Practices for Engaging People with Lived Experience](#)
- [How Can We Share Power with Communities?](#)
- [Resources for Collaboration and Power Sharing Between Government Agencies and Community Power-Building Organizations](#)
- [Activities to Deepen Your Power-Building Analysis](#)

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