



True Health Care for the Homeless
Council on Health and Homelessness



Beyond Mere Principle: Strategies for Truly Partnering with People who Have the Lived Experience in our Work

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Credit: Deidre Young

People with the lived experience of homelessness are regularly stereotyped and face stigma, yet have a lot to teach about the needs and effective solutions to the widespread problems we collectively face. If we want to address these problems on a systemic level, we must start with the spaces that we control: our own organizations. The [National Health Care for the Homeless \(HCH\) Council](#) believes that people have the right to participate in decisions affecting their lives. For over 30 years, we have supported health centers and others who provide health care to individuals experiencing homelessness to build genuine consumer leadership and partnership.

In our world of constant change and a growing need for health care and housing services, it is a challenge to prioritize our resources and energy. However, where we spend our time and money shows what we value. If we value humanizing the people we serve, and learning from the community, we must invest in consumer engagement in governance and leadership. (Please note that occasionally I will refer to people with the lived experience as “consumers”. This is the term that our leaders with the lived experience have chosen for themselves.)

I often find people support the values and principles of engaging people with the lived experience of homelessness in our work but struggle to *operationalize* those principles. Organizations face the usual challenges of engaging volunteers, and struggle against widespread feelings of disenfranchisement and disengagement. Engaging people who lack housing provides additional—and unique—challenges.

Three Challenges to Consumer Engagement and Leadership

- People who do not know where they are going to sleep, eat, or find safety may not be able to consistently attend meetings, secure transportation, access email, or have unlimited phone use.
- People who have high rates of stress, trauma, sleep deprivation, and behavioral health concerns may have varying behavior or communication styles that don't adhere to what might be thought of as “professional” norms.
- People who have been historically marginalized or stigmatized may be resistant to participating in feedback or governance due to negative experiences in having their voices heard and respected.

All too often, organizations try to engage people experiencing homelessness in consumer feedback or other initiatives, only to encounter challenges, struggle to overcome them, become discouraged, and give up. Yet there are ways to overcome these challenges.

The HCH community is accustomed to overcoming challenges and we're committed to continuing to learn and improve in everything we do. We provide health care and support services to people who others categorize as “service resistant.” We restore dignity and respect to people who feel abandoned by their community. We find ways to navigate “broken” systems. We do this by taking seriously the concept of patient-centered care: a non-judgmental, trauma-informed approach rooted in harm reduction. We believe health care and housing are human rights. And we're committed to continuing to learn and

Three Lessons Learned on Consumer Engagement and Leadership

1. Work with your community to develop the necessary structure and supports.

- Devote the necessary resources to make the programming successful (i.e. budget, staff time, space). Ensure transportation, reminder calls, and adequate staff

support. Be mindful of the emotional labor and resources this support requires.

- Create a variety of roles and opportunities for people to engage in small ways and build engagement as they find connection and stability. Roles can include: participating in focus groups, leading focus groups or listening sessions, conducting surveys, providing support to other consumers, becoming engaged in a Consumer Advisory Board, or being a member on the Board of Directors or Continuum of Care.

One way in which we help to build this capacity is to dedicate part of our annual budget to sending about 35 people with lived experience, including NCAB members, to our national Healthcare for the Homeless Conference.

2. Create genuine participation and leadership.

- Allow people to be authentically themselves by supporting their voices, not controlling them. Focus on the message of what people are saying rather than their communication styles or “polish”.
- Ensure your structure and organizational climate provide for open feedback and meaningful participation in the decision-making process, not tokenizing.

For example, NCAB members gather and produce content for their newsletter, “The Consumer Voice”, which serves as a communication tool to carry the voices and messages of people with lived experience. We support by simply editing the newsletter and allowing the content to remain authentic to the writers.

3. Ensure spaces where people feel respected, valued, and where people care for each other.

- Prioritize the emotional climate and wellbeing over the need to complete an agenda. Make sure you allocate enough time so that everyone can participate and share, is on the same page with the issue at hand and can work together to develop solutions.
- Foster healthy relationships and group dynamics to cultivate a safe and supportive environment for everyone.

To create genuine and healthy leadership, NCAB members receive trainings to develop their skills and confidence to be a self-run group. This includes trainings to understand how the trauma of homelessness can affect them as leaders, how to organize with people who have endured trauma, nonviolent communication, and self-

care. This understanding helps to build better leaders, as participants learn how to navigate emotions and identify needs.

Other lessons can be pulled from our Consumer [webpage](#) including our [Quick Guide on Consumer Engagement](#) . You can also [email me](#) for questions or support improve in everything we do.

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