

A Quick Guide on Consumer Engagement in Governance of Health Care for the Homeless Projects

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NATIONAL
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Involvement of people in decisions that affect their lives is a basic principle of human rights. This principle is operationalized in the [legislation establishing health centers](#),¹ which mandates that a majority of the members of a Board of Directors be consumers of the health center's services. Recognizing significant practical barriers to consumer-majority boards for health centers that serve only persons experiencing homelessness, the Health Resources and Services Administration (HRSA) provides for a waiver for those organizations. The National HCH Council's [Quick Guide on Board Composition](#)² provides guidance on HRSA's consumer governance requirements. Complementing consumer representation on Boards of Directors, many HCH projects receive input from homeless Consumer Advisory Boards (CABs). The [National Consumer Advisory Board Manual](#)³ provides guidance for CABs on setting up their internal structures.

Consumer engagement in HCH governance:

- honors the dignity and rights of people experiencing homelessness, consistent with the missions of many HCH organizations;
- brings to program planning and evaluation significant information and fresh perspectives, grounds decisions in the realities of people experiencing homelessness, and improves service delivery;
- breaks down social barriers and promotes egalitarian social change;
- normalizes the process of giving feedback and engaging in decision-making processes;
- provides opportunities for personal growth for consumers;
- can lead to consumer involvement in other aspects of an agency's work, as planners for events like Homeless Persons' Memorial Day, as Community Health Workers, or as peer mentors, for example; and
- satisfies funders and legal requirements.

This guide provides practical tips for organizations in setting up effective, empowering consumer governance structures and supports. The ideas in this Quick Guide were developed through conversations with over 20 key informants: consumer leaders, consumer support staff, and executive leaders of HCH projects who have facilitated consumer leadership both locally and nationally. Some of their direct tips are included in the text boxes.

Process for Developing Consumer Engagement

Step 1: Conduct conversations with consumers, staff, and executive leadership to think through developing the structure and processes. Identify potential allies and bring them into the conversations.

Step 2: Develop a proposal that outlines the strategies and scope of engagement and identifies impacted departments or individuals along with their potential contributions. The plan should integrate consumer engagement processes with current decision-making processes and identify necessary organizational resources.

Step 3: Gather consumer, staff, and leadership feedback on questions and concerns and make any necessary changes.

Step 4: Implement consumer engagement strategies and commit to ongoing evaluation.

Considerations for Consumer Engagement Structures

Intention, planning, structure, staffing, and budget are keys to effective consumer engagement. An agency must have a clear commitment to responding to consumer advice, involving Board, staff, and consumers in planning and establishing mechanisms for consumer engagement. A written plan in the agency's policies and procedures manual is advisable. Dedication of staff time to coordinate and support consumers' involvement in governance is usually necessary. The agency's budget (which can provide for transportation to meetings, replacement of meals missed due to meetings, training, and staff support) is a telling barometer of its commitment.

Ideas about who should provide staff support for CABs

- A member of executive leadership who is able to give insight into clinic operations and directly address concerns around services.
- An individual with a background in social work who is able to share understanding of how to create safe and accessible consumer spaces.

Recruitment and retention of people experiencing homelessness is challenging. Individuals who express concerns or interest in agency operations may be identified by providers, or perhaps by their regular participation in ad-hoc focus groups. One or two interested consumers can recruit others through flyers in the waiting room, or by one-on-one outreach to others. Because turnover will occur naturally as individuals resolve their homelessness or relapse in their disease processes, on-going recruitment is usually necessary. Competing priorities in the daily struggle to survive, health issues, and changing circumstances can interfere with participation and retention, and should be addressed in meeting scheduling and in arrangements for personal support to enable participation. Developing different levels and methods for engagement can be useful in acknowledging differing abilities and interests, but also as a means to develop a ladder to promote increased engagement.

When recruiting or onboarding new Board or committee members, it is important for executive leadership to have a conversation about the role and responsibility associated with the position so that individuals can make an informed decision about the commitment. It is also helpful for potential Board members to have conversations with current members to gain insight into the structure and process.

Developing peer mentorship structures throughout the Board across consumer and non-consumer members was noted as important in providing familiarity and support, expanding understanding of the content of Board meetings, and opportunities for non-consumer members of the Board to humanize the work and broaden their perspectives on homelessness and the health center's services.

The productivity or workflow of consumer advisory boards can also fluctuate over time depending on the environment at the health center, membership, and group dynamics. CABs often do well in providing direct feedback but can need support in understanding the broader organizational structure and industry framework required to develop new initiatives or systems-level changes.

Consumer Advisory Boards in particular are meant to be consumer-led; thus it is important for staff support to give opportunities and space for consumers to facilitate discussions, develop their conflict management skills, and work to organize the group.

Creating open and accessible environments requires patience and additional time, but allows for a broader range of input and helps to ensure fuller and more honest participation. The highly structured culture of most Boardrooms may be unfamiliar or intimidating to consumers, and flexibility may be required to accommodate consumers' differing styles of expression and decision-making. Because many consumers struggle with trauma, mental illnesses, and substance use, agencies need to consider how they are creating spaces where everyone feels safe and is able to contribute in a respectful and meaningful manner.

It is important for health centers to pay attention to potential conflicts of interests for all Board members. Regarding consumers who still receive services at the project, organizations should be alert to the possibility that consumers may receive information about their care providers and should give any such consumers time to process their reactions within a confidential space with executive leadership or trusted Board members.

Power dynamics are very real, and a sole consumer experiencing homelessness on a Board can feel this intensely; agencies can respond by involving multiple consumers on Boards and committees, by establishing peer mentor and support relationships, and by having staff provide context, explanations, and personal support to consumers.

CAB members can struggle with their role within the organization and relationships with staff. It is important to set boundaries, to have honest conversations about responsibilities and expectations, and to establish appropriate means of handling concerns about staff or the organization.

Initial orientation and on-going education and training for consumers can promote their meaningful engagement with Boards and committees, addressing topics such as agency structure, budget and finance, requirements regarding confidentiality, consensus, and other decision-making processes, group facilitation, and conflict resolution. Additional trainings that can help consumers develop their skills as leaders include trauma-informed care, de-escalation, cultural humility, and group dynamics.

Feedback and evaluation processes are necessary to validate an agency's investment in consumer engagement in governance. Clarity in how consumer concerns are communicated to Board or staff decision-makers, and in how those concerns are resolved, is essential to the integrity of the process; methods can include CAB reports to CEOs, dedicated time on Board or management meeting agendas and minutes that are shared, and opening CAB or town hall meetings to all consumers. Feedback loops also must include how CABs are engaging the broader consumer perspective so that they are best able to represent a diverse group of individuals and experiences.

The process of identifying leaders, building relationships, and fostering development can be lengthy and intensive work, but it provides not only fidelity to HCH's social justice principles but also tangible benefits in the delivery and quality of care.

Examples of CAB Contributions to HCH Projects

- Changing the label on prescriptions so patients would not be identified as homeless.
- Recommending calming sounds and increased staff presence in lobby.
- Helping pilot standby appointments and providing feedback on status of changes.
- Lending design ideas for a new clinic.
- Developing a help desk in the lobby to share information about local resources.

¹ Health Center Program Requirements. (Retrieved September 2016) U.S. Department of Health and Human Services. Health Resources and Services Administration. <http://bphc.hrsa.gov/programrequirements/index.html>

² National Health Care for the Homeless Council. (2014). A Quick Guide on Board Composition for Health Care for the Homeless Projects. <http://www.nhchc.org/wp-content/uploads/2015/01/hch-board-composition-quick-guide-final-formatted.pdf>

³ Dailey, E. (May 2009). Consumer Advisory Board Manual for Health Care for the Homeless Projects. National Consumer Advisory Board. http://www.nhchc.org/wp-content/uploads/2011/09/NCAB_Manual-rev-Jan10.pdf