

The Birth of Consumer Advisory Boards at Health Care for the Homeless Programs: A Case Study from Boston

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Recognizing that direct patient feedback creates the most effective policies and programming, health centers have long had a requirement to engage consumers in their organizational governance structures. However, health centers serving only people experiencing homelessness have traditionally had difficulty meeting the 51% consumer board member requirement due to the challenges inherent in serving such a vulnerable population. In order to meet the governance requirement and fulfill the intention of providing meaningful consumer leadership in decision-making, Boston Health Care for the Homeless Program (BHCHP) developed a Consumer Advisory Board (CAB) in 1996. This case study will document the history and growth of this CAB, while sharing their lessons learned to serve as a model and provide guidance for other health centers.

Conception

In Boston in the early 1990s, BHCHP noticed a problem in their community. People were too sick for the shelter or the streets, but not sick enough for the hospital; and struggling with nowhere to go to adequately provide for their health. Therefore, in 1993 BHCHP opened The Barbara McInnis House, the first medical respite facility in the United States to serve those individuals in a dignified and comprehensive way. There were no regulations or rules about how to operate such a program, and no other programs to look to for guidance. They decided to turn to the experts to learn how to effectively run their services--the very consumers who were using the services.

Barry Bock (then-Director at the Barbara McInnis House), and Cecilia Ibeabuchi (Director of Nursing) wanted to do more than gather feedback from surveys or focus groups. They wanted to create a structure for consumers to meaningfully contribute their perspective, shape the conversation based on the issues and needs that they saw, and bring forth their own ideas of ways to improve the program. Furthermore, they wanted this new structure to be consumer-led to further the mission of dignity and client participation in care. These meetings were open to residents to share their experiences living at the Barbara McInnis House and give feedback on changes that the organization was proposing.

Growth of the Consumer Advisory Board

After the initial six months, the group began leading themselves. The first members included Carolyn Smith, Ellen Dailey, Tommy James, Larry Adams, and two community representatives who were trusted by the community, including Reverend Debbie Little and Barbara McInnis (after whom the program was later named). They voted Ellen Dailey as their chair and developed by-laws for how the CAB would be structured and operate, largely based on the Program's Board Governance materials. In retrospect, long-term members say they were able to organize well because the group was cohesive, respectfully challenged one another, worked through disagreements, and stayed focused on the mission.



Consumer Advisory Board, 2004

Initially, the CAB was formed to give a consumer voice around the operations of the McInnis House only; however, shortly thereafter HRSA mandated that all Boards of Directors have 51% consumer governance. BHCHP received a waiver to this requirement, and the CAB took on a program-wide focus. BHCHP has had consumers on the Governance Board for over 20 years, including in the role of Board Chair and Vice Chair. Since that time, the CAB has engaged in a significant number of activities, as seen below.

CAB Activities Throughout the Years

<p>Engagement with Organizational Policies or Programs</p>	<ul style="list-style-type: none"> • Reviewing new organizational initiatives and policies • Developing HIV subcommittee which organizes an annual luncheon, helps promote World AIDS Day, supports overdose awareness projects, and attends program meetings for HIV services to give feedback • Helping to set the organization’s advocacy agenda and agency priorities • Participating in new staff orientation, staff, or program meetings to share insights • Supporting fundraising including starring in videos for sock drives with the Red Sox baseball team • Supporting the work of the “Patient Technology Workgroup” to provide feedback on the patient portal and text reminders for appointments, as well as supporting digital literacy through technical assistance for technology needs of consumers. • Working with the Quality Improvement Committee
<p>Facilitating Consumer Feedback</p>	<ul style="list-style-type: none"> • Attending and facilitating bimonthly focus groups at The Barbara McInnis House to ensure the voices of other consumers were shared with executive leadership • Helping develop patient satisfaction surveys to ensure language access and comprehensive questions
<p>Outreach</p>	<ul style="list-style-type: none"> • Planning and attending health fairs to support access to health care, improve the experience of attendees, and build relationships with consumers and staff • Speaking at panel discussions and storytelling events • Visiting a family shelter in December each year to bring holiday presents • Creating an Ellen Dailey brochure for the National Health Care for the Homeless Council
<p>Developing CAB or CAB Member Products</p>	<ul style="list-style-type: none"> • Creating “Housing Guide” to help newly housed consumers with practical skills and resources that they may need support with during their transition¹ • Developing a video with staff called “New Place, New Problems” to share the struggle of being newly housed²

Strengths of the CAB

Of its 10 current members, two are founding members and three others have been participating for many years. The stability of these long-term members helps to provide constant, uninterrupted support, as well as historical knowledge and experience. Overall, the group feels that they represent a diverse population in a unified manner that helps them provide well-rounded feedback.

The organization continues to support the CAB because it embodies the mission. Resources allocated to the group include administrative staff to help with logistics, and a dedicated budget to support meals, transportation, and stipends. Staff say that they treat the CAB as they would any other working meeting group and ensure that they have all the information that they need to be successful. The three staff members who

attend these meetings have been involved with the CAB since the beginning, allowing them to provide consistency. These staff members include Barry Bock, who is now the CEO, which allows BHCHP leadership to stay grounded in the work and to ensure there is staff present at the meeting who is empowered to make decisions and offer concrete ideas. Every Board of Directors meeting includes a report from the CAB, with the minutes from the meeting provided.

Over the years, the CAB has had a significant impact on both the organization and its members. Here are several examples of CAB contributions over the years:

- In the early days, at the Barbara McInnis House, staff noticed that patients/consumers were missing medical rounds and took the issue to the CAB. They found out that consumers did not know when to expect their provider, so some would miss rounds while smoking. The group decided to set specific times for smoking so no one would miss rounds.
- Consumers raised concerns that the vending machines at the Barbara McInnis House were too expensive. BHCHP took that concern and renegotiated prices with their vendor.
- Several consumers experienced negative treatment from outside health care providers once they mentioned they were affiliated with the “homeless clinic.” BHCHP changed its practice name on prescriptions and appointment cards so that clients were not publicized as experiencing homelessness.
- When the new Barbara McInnis House opened with a porch, the CAB named it the “Serenity Deck.”

Ellen Dailey

Ellen Dailey is affectionately referred to as the mother of the consumer movement in the Health Care for the Homeless community. In 1996, Ellen worked with a public school desegregation program in Cambridge, Massachusetts when health issues led to a hospital stay. While there, her rental home was sold and the grant that funded her work ended. Now homeless and getting post-surgical care at the Barbara McInnis House, Ellen found her mission to ensure the dignity of the consumer voice.



Over the next years, Ellen continued to grow consumer engagement at the BHCHP CAB, and expanded her work nationally through the National HCH Council. She facilitated a growing recognition of the need for consumers in governance and the existence of CABs in other HCH programs, and advocated this approach with the National HCH Council, at its annual conference, and within Council committees. As a result, consumer leaders nationally formed the National Consumer Advisory Board in 2003 to support other consumers in developing and maintaining leadership roles at health centers.

Ellen was described by colleagues as an articulate and fierce advocate who always fought for what she believed was right, especially ending the injustice of homelessness and the inclusion of consumers in the work to end those injustices. Ellen died in 2006, but her legacy lives on.

Challenges of the CAB

BHCHP has always believed that membership should truly represent the community that is served, including those who have struggled with mental health, substance use disorder, complex health needs, and chronic homelessness. The organization and CAB want people who believe in the values, are able to give honest feedback, and will contribute to the community of the Board and the work. Yet it is a challenge to recruit individuals who may still be struggling with housing stability and poor health. The CAB continuously recruits new members through word of mouth, staff recommendations, and CAB member outreach. CAB members regularly visit the Barbara McInnis House, which allows them to get to know current consumers and engage them as potential consumer leaders. Staff members similarly evaluate if their clients could make good CAB members and

recommend them to the support staff. During these outreach discussions, consumer leaders and staff members explain the purpose of the CAB, the work they do, and the benefits of engaging. Individuals who are interested apply and then have an interview with the CAB to determine fit. One significant membership challenge for the CAB came when four longstanding CAB members died within five months. The emotional toll was difficult for both members and staff. It is a reminder of our need for constant recruitment, but also demonstrates the importance of relationships in groups or CABs.

Group dynamics can be hard with any group, yet forming a diverse group of individuals with histories of trauma can add layers of complication. They have misunderstandings but work to forgive and respect each other's perspectives. The group understands that disagreements are expected and demonstrate the care and engagement members are bringing to the work. They acknowledge the work is an ongoing process, and are committed to learning and growing together. To set this tone, the CAB developed "Meeting Etiquette" guidelines that are read at the beginning of each meeting (see below).

Boston CAB Meeting Etiquette

1. Respect, care about, and support each person in the group. The more confidence each feels, the more anxiety diminishes, and the more deeply we can work toward our goals.
2. Putting people down closes them up and is counter-productive.
3. Avoid forcing your viewpoint by an overbearing attitude or barrage of arguments.
4. Try to avoid becoming defensive. Realize that you are among friends. View confrontation as an invitation to self-exploration.
5. Fruitful discussion requires openness to change.
6. Stick to the point. Do not wander.
7. Speak for yourself. Avoid using "we" when you mean "I". Do not speak for the group without giving others a chance to agree or disagree.
8. You are neither therapist nor judge. Your role is not to set other people straight nor to solve their problems, but to support, help, and encourage.
9. Express disagreement as your idea not as absolute truth. Find common ground and areas of agreement before setting forth points of difference.
10. Say it in the group. The things you say to your friends about the group before, after or between meetings are often the very things which should be said in the group. There should be only one conversation at a time going on in the group.
11. Make the meetings. If one person misses a meeting, the dynamics of the group change. And it often happens that the one who was absent cannot be brought up-to-date because he did not experience what really happened. The group needs to have you present.
12. New Business is a time for items not on the agenda or personal issues. Do not monopolize agenda time with your own personal/medical history.
13. Meetings must be run in a constructive manner in order to achieve our goals. We must follow the agenda and remember that health care is our primary focus.

Lessons Learned

Members say that they come back for three reasons: they feel respected, they have authentic relationships, and they are productive. It takes more time to ensure everyone understands the issues, is able to participate in an open discussion, and come to a consensus decision about how to move forward. The CAB has learned to pace the meeting to ensure everyone understands the discussion and decisions. Members say that they feel safe with this group, that they can share freely their thoughts and opinions and they are heard and respected. People who have experienced trauma or stigma can feel disconnected and disrespected, hence BHCHP and the CAB have worked to create a culture of respect and connection to heal from those experiences. Members regularly get together outside of meetings to build meaningful relationships with each other that increases their trust and bond. Finally, they appreciate that the group participates in active decision making together with a focus on all BHCHP consumers and sees the impact of its work directly on improvements to services.

Conclusion

BHCHP's CAB gives consumers a voice in a respectful way that helps them eliminate stigma and make a true difference. The benefits of this work for consumers and the organization are practical and philosophical. Providing for a CAB allows for consistency with core values and sends a strong message to staff and clients in demonstrating commitment to values and quality services. BHCHP is looking forward to the continued strength and growth of their CAB.



Consumer Advisory Board, 2017

Resources

1. Joanne Guarino. (April 2015). *Housing Guide: Tips and Tools for a Successful Housing Experience*. Boston Health Care for the Homeless Program Consumer Advisory Board. Available at: https://www.bhchp.org/sites/default/files/Boston%20Health%20Care%20for%20the%20Homeless%20Housing%20Guide_English_Final.pdf
2. Larry Adams. (June 2017). *New Place, New Problems*. Boston Health Care for the Homeless Program Consumer Advisory Board. Available at: <https://www.youtube.com/watch?v=EX-Nz2RDVZs>

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