

# Evolution of the National Consumer Advisory Board

## A Case Study in Consumer Leadership

December 2020



Consumer involvement in governance is a unique feature of Health Care for the Homeless (HCH) programs and other federally supported Health Centers.<sup>1</sup> The National Health Care for the Homeless Council (the Council) acknowledged in its founding principles<sup>2</sup> that “all people have the right to participate in the decisions affecting their lives,” yet took time to include consumer participation in its' governance. This document summarizes the development and successes of the independent National Consumer Advisory Board (NCAB) within the Council.

### Organization Background

The Council began as a mutual support group of the 19 HCH demonstration projects established by the Robert Wood Johnson Foundation in 1985. Then, in 1987 the Stewart B. McKinney Homeless Assistance Act formally established a federal HCH program, which provided operating grants to the original 19 projects and 42 other entities. The Council continued with support from the Comic Relief telethons<sup>3</sup>, hired its first staff in 1990, and expanded as a membership organization.

In 2019, the federal HCH program included 300 grantees in over 2,000 locations providing comprehensive health care to over 1 million people experiencing homelessness.

In 1991, Health Resources and Services Administration (HRSA's) Bureau of Primary Health Care contracted with the Council to identify the needs of clinicians in HCH programs. The survey revealed a sense of isolation among clinicians and resulted in the creation of an HCH Clinicians Network to represent clinicians' interests in the Council structure. The Clinicians' Network started as a self-governing committee that elected a Steering Committee to guide their work. Using federal funding, the Council provided a dedicated staff person to the Clinicians' Network and subsidized travel to Network meetings. This experience later provided the model for NCAB.

In 1996, Congress passed the Health Center Consolidation Act, which merged the federal HCH program with community, migrant worker, and public housing health centers. Among other provisions, the HCH grantees were now required to have Boards of Directors composed of 51% consumers. Understanding that grantees serving people experiencing homelessness exclusively might face



NCAB Steering Committee Members 2013

<sup>1</sup> Public Health Service Act Section 330 <https://uscode.house.gov/view.xhtml?req=granuleid:USC-prelim-title42-section254b&num=0&edition=prelim>

<sup>2</sup> National Health Care for the Homeless Council Statement of Principles <https://nhhc.org/who-we-are/get-involved/statement-of-principles/>

<sup>3</sup> History of Comic Relief <https://www.comicrelief.com/about-comic-relief/history/>

difficulties in creating and maintaining majority consumer Boards<sup>4</sup>, Congress allowed waivers of this requirement. HCH grantees were, however, required to engage consumers in other ways, such as satisfaction surveys, focus groups, feedback boxes, consumer advisory committees, and non-majority participation on the Board. The Council was chosen to assist grantees in meeting the requirement, and turned to the experience of an Organizational Member, the Boston HCH Program.

## The Birth of NCAB

In 1993, the Boston HCH Program created the Barbara McInnis House, the first medical respite care program for people without homes who needed a place to recover after hospitalization.<sup>5</sup> The McInnis House Director Barry Bock and Director of Nursing Cecilia Ibeabuchi assembled a group of consumers to help shape the program since there was no guidance available at that time for medical respite.<sup>6</sup> When the new majority-consumer Board requirement was announced, Boston already had a Consumer Advisory Board (CAB) to expand for the full program. At the 1997 National HCH Conference, Ellen Dailey, the Chair of the Boston CAB, presented a workshop on their model. Gradually, other HCH projects implemented and adapted the CAB model in their own organizations. In 2003, the Council invited consumers to discuss the formation of a national CAB to guide the work of the Council and ensure a national voice for consumers. Four consumers attended this meeting and became the founding members of NCAB: Ellen Dailey (Boston, MA), Veronique Moore (Kalamazoo, MI), Sarah Davidson (San Antonio, TX), and Ulysses Maner (Ft. Lauderdale, FL).

Early discussions between NCAB and the Council focused on NCAB leadership, their role within the Council, and how they could effectively engage with the Council's wide range of members. Ultimately, the founders sought to promote the voice, experience, and expertise of people experiencing homelessness in governance of health centers and the Council, and in broader advocacy regarding health care quality, access and delivery systems.



After losing her housing during a hospital stay, the late Ellen Dailey wound up at the Barbara McInnis House, a medical respite program of the Boston HCH Program. While there, Ellen found her mission to ensure dignity and a voice for people experiencing homelessness. She was the first chair of the McInnis House CAB, chair of the Boston HCH Program Board of Directors, and the first chair of NCAB. In her memory, the NCAB established the annual Ellen Dailey Consumer Advocate Award.

<sup>4</sup> The difficulties include transience, lack of transportation, and a high incidence of addictions and mental illnesses.

<sup>5</sup> There are now 102 Medical Respite programs in the United States. The Respite Care Providers' Network exists within the National HCH Council on the same basis as the Clinicians Network and NCAB.

<sup>6</sup> The history of the McInnis House and Boston HCH CABs is featured in a case study available at [https://nhchc.org/wp-content/uploads/2019/08/boston-cab-case-study\\_final.pdf](https://nhchc.org/wp-content/uploads/2019/08/boston-cab-case-study_final.pdf)

**These early NCAB leaders wanted to ensure that consumers could lead themselves and share their perspectives honestly and openly.** For many, this was their first time being a part of a self-run group within a network of professionals. They needed time to understand each other and be comfortable with a deliberative and inclusive decision-making process. These early conversations -- working through how to balance decision-making between the Council and NCAB, determining the vision and structure of NCAB, and ensuring that NCAB was an inclusive space for consumers -- had some tense moments. NCAB insisted that it be an "independent" organization, empowered to make its own decisions. The Council sought to incorporate the consumer voice "within" the Council. The tension was resolved by acknowledging NCAB as a standing Individual Membership Group within the Council, with representation on the Board of Directors like that of the Clinicians' Network and the Respite Care Providers Network. The Council's practice of consensus decision-making, wherein any participant can bring forward a proposal or block a decision, and which insists on respect for each participant, ensured that NCAB's voice would be equal to all others and that NCAB's own space would be safe for consumers. Individuals present for these conversations say they were successful because all parties genuinely listened to each other, understood they held a common goal and principles, and were not afraid to address difficult topics.

**NCAB and the Council also held a number of important conversations about what 'inclusion' meant in terms of human rights.** NCAB believed that if they wanted to represent people experiencing homelessness, they needed to be authentic and ensure the group included a diverse range of communities, experiences, and abilities. They discussed how to include those who have been historically marginalized, have differing abilities, are struggling with health conditions, or housing instability. A commitment to a human rights approach provided both substantial unity within the group and a platform for members' advocacy activities.

**NCAB determined they would be a self-run group, supported by the staff of the Council.** The Steering Committee would be composed of only consumers, originally four members that has grown to 15 since. Their initial priorities were to promote CAB development and encourage the growth of consumer leaders. NCAB worked via monthly conference calls and during an annual meeting at the National HCH Conference. Their first project was to develop a CAB Manual, which Ellen Dailey wrote and published with the support of NCAB and the Council in 2003. They also used the National Conference to network with administrators and clinicians, and



Founding Members of NCAB (from left) Ellen Dailey, Sarah Davidson, Ulysses Maner, Veronique Moore

encourage them to develop their own CABs. In the early years, NCAB members could often be found in the lobby of the National Conference hotel talking to everyone about the importance of including the consumer voice in their work.



Early NCAB members as "Lobbyists" at the Conference

NCAB developed into a vital element of the National Council, ensuring consumer representation in every committee or work group of the Council, and participating in advocacy activities such as Congressional briefings and meetings with federal officials. Over the years, NCAB also developed its own projects. The following table explains these projects and their development.

**The Evolution of NCAB Projects**

Project	Early Version	Changes over the Years	Current Version
<b>Local CAB Development</b>	Ellen Dailey wrote the first manual for local CABs in 2003 with the support of Boston HCH staff and the Council.	In 2009, NCAB and Council staff updated the Manual. With federal financial support, NCAB Steering Committee members began providing on-site assistance to local CABs.	In 2020, NCAB revised the <a href="#">CAB Manual</a> to include more in-depth operational content, added sample documents, and created questions for CAB development.
<b>Promoting National Events</b>	Around 1997, the Council and NCAB began to cosponsor <a href="#">Homeless Persons' Memorial Day</a> (with the National Coalition for the Homeless), which occurs on the winter solstice and honors those lost to homelessness.	In 2015, Care for the Homeless in New York City developed the <a href="#">Summer Solstice Event</a> , which complements HPMD and honors the successes of those who have overcome homelessness and affirm that we can end homelessness.	NCAB supports Homeless Persons' Memorial Day, the Summer Solstice, and <a href="#">HCH Day</a> (presented by the National Association of Community Health Centers as a part of Health Center Week).
<b>Consumer Participation Outreach Survey &amp; research</b>	In 2004, Paul Boden, Director of the San Francisco Coalition of the Homeless, introduced NCAB to the idea of <a href="#">surveying consumers as part of a conference workshop</a> . Boden helped NCAB develop initial surveys,	The initial surveys were short and intended to be easily conducted by many consumers. A 2010 survey on violence in the homeless community was conducted as a formal research project. Results were <a href="#">published in 2014 in the Journal of Violence and Victims</a> . After this study,	After several intensive research surveys, NCAB wanted to ensure these surveys were used to impact change. Thus, NCAB developed a two-year process. The first year is a short, easy survey. The second year focuses on developing and implementing

	trained members to conduct surveys in their communities, and helped them analyze the results.	NCAB continued with a more intensive research process.	recommendations that emerge from the survey.
<b>Conference Engagement</b>	NCAB would gather in the lobby to talk with attendees about the value of CABs. NCAB held a regular Business Meeting of consumers to talk about CAB development and vote on the Steering Committee members.	In response to NCAB, the Council obtained federal funds to bring more consumers to the conference. NCAB developed a mentorship program to support these consumers and build relationships. NCAB has assumed responsibility for organizing a public rally. NCAB also presents the Ellen Dailey Consumer Advocate Award which honors someone who has experienced homelessness and advocates on behalf of the community.	NCAB now facilitates an orientation and meeting for all consumer attendees, mentors new attendees, supports the rally, and facilitates a four-hour training. The training has focused on trauma-informed consumer leadership for the past four years. About 40 consumers now attend each National Conference.
<b>Storytelling</b>	The first Consumer Advocate introduced NCAB to 'Strategic Sharing' as a means of effectively talking about experiences with housing and health care in order to increase awareness and impact policy change.	NCAB continued to hold trainings and workshops on storytelling. In 2017, NCAB developed its <a href="#">own storytelling manual</a> focused on effective strategies for sharing experiences of homelessness and the emotional implications of storytelling for the speaker and audience.	NCAB continues to promote storytelling as a means of challenging stigma, supporting the authentic consumer voice, and pursuing policy changes that prevent and end homelessness.
<b>Newsletter</b>	NCAB developed its initial newsletter in 2012, with consumers sending articles or art to be featured. The Steering Committee then acted as editors, choosing the content and formatting the newsletter.	After Council staffing and NCAB membership changes, there was limited capacity to complete the newsletter and fewer content submissions. The Steering Committee voted to pause the project for the near future.	In 2018, the Steering Committee restarted the newsletter, with Steering Committee members authoring the sections and constructing the layout. The new version, <a href="#">The Consumer Voice</a> , is currently produced four times per year.

## Challenges over the Years

- **Ensuring consumers have the resources, skills, and support to equitable participation.**
  - Early on there were growing pains for the Council in understanding how to engage people without homes in national level technical assistance work. For the first seven years, various Council staff supported NCAB in addition to their other work. In 2011, the Council established the first Consumer Advocate position. That staff person said her role was to “give NCAB the responsibility but assist them with things beyond their capacity.”
  - Effective consumer participation in NCAB often requires the active support of the leadership at the local HCH programs where they receive care. This includes anything from access to a phone for conference calls to making travel plans for people who have never been on a plane. The Council originally asked local programs to handle the costs of meals and incidentals but learned that a Council cash per diem was easier for both consumers and local projects. Consumers who have become staff of local projects may need permission to participate in NCAB during working hours. Sometimes, large gatherings like the national conference can trigger a PTSD response or a relapse in recovery processes, and attention from someone from home is needed.
  - The costs of NCAB activities have largely been supported by a Cooperative Agreement between the Council and the Health Resources and Services Administration.

### NCAB by the Numbers

<b>Steering Committee Members</b> (estimated over the years)	<b>30</b>
<b>NCAB Individual Members</b> (as of December 2020)	<b>1,500</b>
<b>National CABs</b> (with connection to NCAB)	<b>37</b>
<b>Number of consumers we brought to our last conference</b> (2019)	<b>43</b>
<b>Number of consumers we have brought to our conferences</b> (estimated over the years)	<b>300</b>
<b>Number of NCAB published documents</b> (i.e. consumer survey, manuals)	<b>17</b>
<b>Number of NCAB newsletters</b>	<b>20</b>

- **Balancing empathy and understanding with achieving tasks and deadlines.**
  - All groups struggle with group dynamics, productivity, and participation; yet groups of people who have experienced trauma must intentionally develop empathetic and supportive responses. Over the years, NCAB has had members who did not participate in calls, were consistently late, or did not completing their tasks. When this would occur, NCAB would reach out to provide support, including personal or professional guidance that fellow members may need. When support and outreach did not work, NCAB held majority votes to remove members who were not meeting their expectations. In 2016, NCAB created the Peer Advocate position on the Steering Committee, with the member's sole responsibility to provide support to the other members.

- As consumers within a professional clinical environment, NCAB struggled with how they gain credibility amongst the HCH community and themselves. There have been times when members felt judged for not being as polished. They also believe the community respects their perspective and sees their value, particularly over time seeing their work and dedication. The group has also struggled amongst themselves about how, or whether, they want to present as professionals, and how to balance that dynamic while remaining accessible and authentic.
- **Connecting with local consumers to build relationships and develop new national leaders.**
  - NCAB's connection with local consumers comes primarily through local HCH leadership and the National Conference. It has taken a significant amount of time and effort to develop local CABs, identify national consumer leaders, and create a body of work that attracts attention from organizations and local consumers.
  - In 2012, the Steering Committee created a Regional Representative position to connect NCAB with local CABs. This role expanded connection to local CABs, however some health centers interpreted outreach as an attempt to enforce compliance. Regional Representatives continue to support consumer development and dispel that belief.

### Strengths of NCAB

- **Creating a welcoming and inclusive space for consumers to engage.**

- The NCAB has many similar recruitment stories. Individuals attend a conference as presenters or new attendees and are introduced to members of NCAB who take them under their wings. Members of NCAB take their responsibility to act as role models and mentors seriously and actively work to create a family environment.
- NCAB elects its new Steering Committee at its Annual Business Meeting during the National Conference. These meetings continue the NCAB tradition of consensus decision-making where all voices are heard and respected. This can occasionally lead to tense moments, but NCAB works to ensure all consumers have the right to share their experiences and opinions.



NCAB Steering Committee and Council staff at their 2010 Planning Meeting



NCAB Steering Committee and Council staff at their 2019 Planning Meeting

- **Centering the consumer voice.**

- Throughout the evolution of NCAB, there has been a consistent focus on how to improve services for people experiencing homelessness and include as many consumers as possible in local and national work.
- NCAB understands its leadership role and ensures that its work demonstrates that consumers are equal partners in this work who deserve to be taken seriously.

- **Continuing to learn and grow as individuals, advocates, and leaders.**

- NCAB's annual meetings consistently incorporate trainings for Steering Committee members based on group-identified topics. NCAB has had trainings in public speaking, conflict resolution, conducting research, meeting facilitation, consensus decision-making, trauma-informed practices, and non-violent communication.
- NCAB's mentorship program encourages peer learning. NCAB members often say mentorship is one of their favorite activities. It has allowed them to learn about what is happening in communities across the U.S. and better support the work.

“In the beginning, I felt overwhelmed and things were over my head. However, I never felt like I did not belong or they did not appreciate me being there. It took time to feel comfortable, but having “important people” in the HCH community take the time to talk to me, and really listen, made me feel comfortable. It feels like we are all in this together and our family keeps growing.” - **Amy Grassette, former NCAB Chair**

## Conclusion

Despite their personal circumstances or health conditions, NCAB members demonstrate incredible enthusiasm to engage consumers in this work. NCAB has brought numerous benefits to the HCH community. John Lozier, the founding Executive Director of the Council says, “NCAB has encouraged us to respect our clientele in ways we might not have before. They have built incredible consumer leaders who are a central part to the deliberations of the Council. We know our work would not be legitimate without them.”





**Learn more about NCAB at [www.nhchc.org/consumers/ncab](http://www.nhchc.org/consumers/ncab)**

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