



From Recuperation to Life-Long Leadership: Consumer Governance in Medical Respite

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People experiencing homelessness face numerous challenges when discharged from the hospital with no safe or stable place to heal. Medical respite care programs were developed as a solution to this problem by providing a transition from the hospital, for those without homes. Because there is generally no legal, regulatory, or licensing framework at the state level for medical respite programs, the National Health Care for the Homeless Council and the Respite Care Providers' Network developed programmatic standards to ensure safety and quality of care. The standards include the importance of consumer feedback to ensure the programs are meeting the needs of the population. Thus, following the model that emerged from Health Care for the Homeless (HCH) Consumer Advisory Boards, medical respite leaders are increasingly working to engage current and former clients in service planning and evaluation to determine if their programs are providing access to quality services. As medical respite programs are unique settings, this paper will address some of the challenges to consumer engagement, strategies for overcoming these challenges, examples of consumer engagement in medical respite programs, and provide resources for further information.

What is Medical Respite Care?

Medical respite care is defined by the National HCH Council as acute and post-acute medical care for people experiencing homelessness who are too ill to recover from a physical illness or injury on the streets or in a shelter, but not ill enough to remain in a hospital. These programs offer individuals a safe environment, access to medical care, and various supportive services needed in the transition to wellbeing.

Currently, there are 80 known medical respite programs throughout the United States, but the specifics of these programs vary widely between programs based on the unique characteristics of each community.

- **Services:** medical care, case management, patient navigation, transportation, meals, benefits enrollment, housing referrals and placement, job training and placement, behavioral health therapy, and hospice.
- **Facility Type:** apartments, motels, homeless shelters, transitional housing programs, assisted living/nursing homes, substance use treatment programs, and stand-alone facilities.
- **Program Size:** Average 21 beds, but range from five to over 100 beds.
- **Length of Stay:** Average stay is 30 days but range from a few days to 1 year (determined by medical need).

What is Consumer Engagement?

Consumer engagement takes client self-determination from the provider level to the systems level. It is not only about partnering with consumers to consider their choices and develop an individual care plan that best suits them, but it is also about inviting them to participate in the governance structures of the organization to shape the services they receive.

Many organizations use satisfaction surveys to get input on how they are providing care. Consumer engagement in governance goes beyond passive feedback, and works toward engaging clients in proactive partnership and supporting their leadership. It involves organizational structures and supports that invite consumers to the decision-making table in a meaningful way, work together to identify the needs of the community and develop solutions. This engagement can include participation and leadership of focus groups, listening sessions, agency events, and/or committees (including membership of Consumer Advisory Boards or Board of Directors). These options are not mutually exclusive, and can often be developed to build off each other.

Consumer Engagement in Medical Respite Care Programs

Medical respite programs help individuals find stability and health through quality care, dignity, and empowerment, which is provided through trauma-informed approaches and active involvement of consumers as partners in their recuperation process. These are the same fundamentals of consumer engagement generally, which perfectly positions medical respite programs to create these opportunities. As with other services or programming, there are some important considerations in implementing consumer engagement.

Process for Developing Consumer Engagement

*Taken from *Quick Guide on Consumer Engagement in Governance at HCH Programs (see Resources at the end)*

- **Conduct conversations with consumers, staff and executive leadership** to develop the structure and processes for consumer engagement mechanisms. Identify potential allies and bring them into the conversations.
- **Develop a plan** that outlines strategies, scope of engagement, and impacted departments or individuals along with the potential responsibilities. The plan should integrate consumer engagement processes with current decision-making processes and identify necessary organizational resources. The plan can start small and give space to grow as new consumer leaders are recruited and systems and structures are developed.
 - Note: A comprehensive guide for an organizational implementation plan can be found in *If You Build It, Will They Come? (see Resources at the end)*
- **Gather consumer, staff and leadership feedback** and concerns and make any necessary changes.
- **Implement consumer engagement strategies and commit to ongoing evaluation.**

Creating Organizational Structure and Supports

Building consumer leadership and a supportive organizational structure takes time, resources, and energy.

When determining the necessary resources, consider the direct costs of supporting consumer leaders, as well as the indirect costs of recruiting, training, and managing this work. Organizations and staff support need to manage the administrative and leadership development tasks of this work.

On the administrative side, organizations should:

- Coordinate logistics of organizing a meeting and meeting space for people at the medical respite program or alumni (including reminder calls)
- Record the minutes and support developing the agenda with consumer leaders
- Report questions or feedback to the appropriate staff
- Promote the role of consumer engagement in the broader organization

To support the leadership development of consumer leaders, organizations should:

- Assist the group and members in defining goals, and work towards achieving those goals
- Cultivate ways for the group and members to develop the knowledge, skills, and opportunities to grow
- Create and ensure healthy group dynamics
- Support the work while ensuring it is consumer-led

Feedback Loops and Decision-Making

Feedback cannot go into a black hole. If the goal is to develop a decision-making structure that incorporates consumers in planning, implementation, and evaluation, organizations need to build the steps to get there. Plan where feedback goes, who is responsible for conveying it and receiving it, and the report-back mechanism so people know what was done with their input. Some programs have found it helpful to have a decision-maker in the focus group, Consumer Advisory Board meeting, or Board of Directors meetings so they can hear the issue firsthand and address questions in the moment.

Creating Safe and Supportive Spaces

Environments, meetings, and interactions must ensure dignity, create safety, and foster empathy through a trauma-informed lens. Doing this will increase the desire and dedication of consumer leaders to become and stay involved as well as help people heal from trauma, re-build social supports, and feel heard and validated. It is important to achieve this through a non-judgmental and open-minded approach to behaviors, communication styles, attention to emotions and the emotional climate of meetings, and cultivating relationships within the group.

Find ways to share power with consumer leaders. Engagement opportunities like participating in focus groups or listening sessions are different than consumer leadership opportunities that allow consumers to guide the work of the organization.

Recruitment

Relationships are critical for successful recruitment. When connecting with current consumers or alumni, find out about their interests and passions, their goals and skills, and then connect those responses to meaningful activities. All staff members and consumer leaders should be considering the engagement potential of the current consumers and recommending potential new leaders.

Advertise and promote these opportunities often and in a variety of ways. People may need to hear about opportunities multiple times before they engage. Promote these opportunities on fliers, in groups, and with providers.

Organizations should create a “ladder of engagement” that allows for small roles to build into larger ones as individuals find stability, build skills, and deepen commitment.

Ladder of Consumer Engagement for Medical Respite Programs

- **Provide consumer satisfaction surveys** for patients to complete during their stay or at discharge.
- **Conduct exit interviews** to receive honest and open feedback about their experience.
- **Hold weekly listening sessions** that provide space for feedback, concerns, and suggestions about services, policies, or care environment.
- **Conduct regular focus groups on specific topics** such as admissions criteria, creating safe space, or TV policy.
- **Develop a Consumer Advisory Board** for the medical respite program that engages current consumers and alumni in a consumer-led group that is directly tied to the organization’s decision-making process.
- **Reserve one or more positions on the Board of Directors for a client representative.**

Specific Challenges for Medical Respite Care Programs

Medical respite programs have specific challenges when it comes to consumer engagement due to the short-term nature of services, and capacity and resources that are more limited than health centers and other venues.

- The short-term nature of services can make it difficult to build long-term connections and relationships, while the focus on acute medical care often emphasizes the immediacy of personal wellbeing over program improvement.
- Limited funding means that programs usually have to prioritize client care over consumer engagement.
- Programs located in hotels or apartments (or other more isolated spaces) make it more difficult to build community amongst clients. Those programs collocated with other service providers may be constrained to do ongoing work with consumers after discharge.
- More limited staff makes it difficult to build in dedicated time for supporting consumer engagement.

Strategies for Success

Lessons learned from other areas of the HCH Community can be applied in the medical respite care environment (see resources listed at the end). For the specific challenges listed above, however, below are some strategies to consider:

- Build relationships with alumni starting when clients enter the program and ensure that they know about alumni support options when they are discharged.
 - Medical respite programs that belong to larger organizations like Health Centers have more opportunities to stay in touch with consumers and maintain their relationships. These programs can also work to connect consumers with the organization's consumer groups or governance structures, such as Consumer Advisory Boards or the Board of Directors.
- Create time and space for consumer engagement in program improvement, which can directly impact more meaningful and fulfilling care for current and future consumers.
- Develop community space where both staff and consumers can connect, build relationships, and have discussions or engage in group activities.
- Encourage staff who have relationships with consumers to engage in discussions about structural causes of homelessness and needed responses.

Medical respite programs can consider a variety of specific engagement structures or mechanisms that meet their individual needs, resources, and capacity.

Examples of Consumer Engagement at Medical Respite Programs

Convalescent Care (Baltimore, Maryland)

Background: This medical respite program is part of the Health Care for the Homeless health center and is located in a nearby shelter. The program serves a maximum of 25 individuals at any given time providing shelter, meals, nursing, case management, and medical on-call services.

Weekly Residents Meetings: A community health worker leads weekly meetings to focus on what clients want to improve about their dorm. These meetings can be safe spaces to share concerns about the environment, other clients, or treatment, as well as suggestions for improvement. This information is shared with the program director or addressed with the partnering agencies. When one solution is not feasible, the organization attempts to determine if there are other ways to address the need or concern. They are also working on having a program alumni come to those meetings once a month.

Local Engagement: On one day each year, Health Care for the Homeless staff and consumers travel to the state capital to speak with policymakers about issues that affect their lives. As part of the larger agency, Convalescent Care staff have participated in this event for a number of years, with clients learning about health and housing issues and participating in the discussion. A few years ago, the program had an intern that was connected with the clinic's consumer engagement work and was able to facilitate the connection between client engagement in these activities and the Consumer Advisory Board. This relationship improved the ability to link medical respite consumers to local and organizational client opportunities, and they are working on a plan for how to revive that bond.

PrimaryOne Health (Columbus, Ohio)

Background: This medical respite program is operated by the Health Care for the Homeless program within a larger health center. They currently have six beds at a local shelter, and provide case management, transportation, and meals for consumers.

Consumer Advisory Board (within larger organization): Their Health Care for the Homeless program has a CAB with 15 members. On the CAB, there is not a position set aside for the medical respite program specifically because they are concerned that reserving seats for specific services could separate consumers from each other or feel tokenizing. The current CAB has several members who are alumni of the medical respite program, and works on issues that are focused on consumer satisfaction, addressing issues around homelessness within the larger health center, and engaging in local strategic plans to address housing and homelessness. The work is driven by the consumers who set the priorities and agenda, with the support of staff. At the medical respite program, the community health worker informs clients about the CAB and works to connect clients to the CAB to maintain the respite program in that conversation. Many of the short-term respite consumers are transitioned into long-term Health Care for the Homeless clients so their engagement continues.

Ascending to Health Respite Care (Colorado Springs, Colorado)

Background: This organization operates both medical respite and permanent supportive housing programs. They have 16 respite beds in a local homeless shelter and can expand that capacity to 26 through the use of local hotels. Their supportive housing program currently has 10 apartments, with waitlists available to those leaving the respite program. Services at both programs include case management, mental health and substance abuse counseling, and health education.

Consumer Advisory Board: Their program has a Consumer Advisory Board (CAB) currently made of five members: two from the current medical respite program and one from an older medical respite program. Their CAB was developed after the Executive Director learned about CABs from the National HCH Council and the National Consumer Advisory Board. He heard organizations and consumers stressing the importance and benefits of consumer leadership and resolved to start a CAB at his own organization. He began with getting staff and alumni buy-in to the CAB, reaching out to old program alumni. They reviewed resources like the CAB Manual but wanted support in how to specifically do this work in a medical respite program. In 2013, they received technical assistance from the National HCH Council on how to start a CAB. From these experiences, he states, “the group gained a sense of place and purpose in the CAB’s role in the program, community, and with each other.” They figured out where they could have influence, how to analyze policies, create leadership, and develop an authentic consumer-led structure with a place in the decision-making process.

The CAB’s work is focused on program and care provision improvement, supporting current consumers in both programs, and developing policy statements on important events in the community. The group regularly interacts with consumers and provides feedback on what is happening from their perspective, reviews proposed policy or practice changes, and works with staff to develop solutions. One example of this feedback includes creating structure around transportation logistics and discharge processes from the hospital to the program. The CAB also acts as a grievance board for the permanent supportive housing residents. When housing clients violate rules (unless it involved illegal activity or violence), they are given the chance to meet with the CAB to talk about why the rules exist so they can see the larger picture and get support from their peers, rather than face punitive actions or eviction. Furthermore, the CAB has looked outside the program to weigh in on issues relevant to health and homelessness. They have written several policy papers and presented to their city council on issues such as panhandling and camping.

The CAB sets their own agenda and priorities, but staff also bring policies and procedures to the group for feedback. They meet bi-weekly and have a dedicated staff person who coordinates the logistics of the meetings and provides direction to the group if asked. The Executive Director also sits in on the meetings as he is available to hear directly from the consumers about important issues at the organization or in the community. The chair of the CAB also sits on the organization’s Board of Directors to provide them updates on the CAB’s work.

Conclusion

Developing consumer engagement and feedback mechanisms helps medical respite programs fulfill their mission of access to quality care and self-determination. The feedback gained can improve the program in a variety of ways for staff and consumers.

It can also help the organization develop consumer leaders. This engagement can help people develop leadership skills including effective communication, public speaking, critical thinking, and relationship building. These skills can be taken into a variety of spaces outside of consumer governance. They can also be used through storytelling to share the needs of people experiencing homelessness and the benefits of the medical respite program for funders, potential partners, legislators, and the broader community.

Resources

Consumer Engagement

- *Quick Guide on Consumer Engagement in Governance of Health Care for the Homeless Projects*. September 2016. National Health Care for the Homeless Council. Available at: <https://www.nhchc.org/wp-content/uploads/2016/11/quick-guide-on-consumer-engagement-formatted.pdf>
- *If You Build it, Will They Come? Recruiting and Retaining Consumers Experiencing Homelessness in Health Center Governance*. June 2018. National Health Care for the Homeless Council. Available at: <https://www.nhchc.org/wp-content/uploads/2018/06/final-consumer-recruitment-and-retention-brief.pdf>
- *Consumer Advisory Board Manual*. May 2009. National Consumer Advisory Board. Available at: http://www.nhchc.org/wp-content/uploads/2011/09/NCAB_Manual-rev-Jan10.pdf
- *Guidance for Consumer Advisory Board Support Staff*. August 2017. National Health Care for the Homeless Council. Available at: <https://www.nhchc.org/wp-content/uploads/2018/01/cab-support-staff-guidance.pdf>

Medical Respite

- *Defining Characteristics of Medical Respite Care*. 2011. Respite Care Providers Network. Available at: <http://www.nhchc.org/wp-content/uploads/2011/09/RespiteDefiningFinal1.pdf>
- *Standards for Medical Respite Programs*. October 2016. National Health Care for the Homeless Council. Available at: <https://www.nhchc.org/standards-for-medical-respite-programs/>
- *Medical Respite Tool Kit*. Available at: <https://www.nhchc.org/resources/clinical/medical-respite/tool-kit/>
- *Directory of Medical Respite Programs in the U.S.*

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